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LOMA LINDA UNIVERSITY
School of Science and Technology
In Conjunction With
Faculty of Graduate Studies

Parental Factors Impacting Neurobehavioral Late Effects
in Latino Pediatric Cancer Survivors

by

Pamela R. Perez

A dissertation submitted in partial satisfaction
of the requirements for the degree of
Doctor of Philosophy in Experimental Psychology

December 2011

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Each person whose signature appears below certifies that this thesis in his/her opinion is adequate, in scope and quality, as a thesis for the degree Doctor of Philosophy.

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ALL	Acute Lymphoblastic Leukemia
CNS	Central Nervous System
CRT	Cranial Radiation Therapy
DNA	Deoxyribonucleic Acid
ITC	Intrathecal Chemotherapy
IQ	Intelligence Quotient
NHL	Non-Hodgkin's Lymphoma
HRQOL	Health Related Quality of Life
MTX	Methotrexate
SES	Socioeconomic Status

ABSTRACT OF THE DISSERTATION

Parental Factors Impacting Neurobehavioral Late Effects in Latino
Pediatric Cancer Survivors

by

Pamela R. Perez

Doctor of Philosophy, Graduate Program in Experimental Psychology

Loma Linda University, December 2011

Dr. Susan Ropacki, Chairperson

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While the survival rate for children with cancer has increased markedly over the past 50 years, the side effects resulting from cancer and cancer treatment have become a major concern for health care providers and families alike. Survivors of childhood cancers are at risk for late occurring sequelae, called late effects, which are associated with disease, chemotherapy, radiation, and surgery. Neurobehavioral late effects are some of the most debilitating late effects found, particularly in survivors of central nervous system (CNS) cancers. The purpose of this study was to explore the impact of clinical and sociodemographic parenting factors on neurological late effects in Latino pediatric CNS cancer survivors. SEM was used to explore the hypothesis that higher parental knowledge, self-efficacy, pro-learning behaviors, and level of acculturation would have an impact on child neurocognitive function and health related quality of life in cancer survivor children. A sample of 73 Latino parents and caregivers were used in this sample. It was found that parent knowledge and self-efficacy indirectly impacted neurobehavioral late effects through child's quality of life. It was also found that more highly acculturated

parents tended to display more pro-learning behaviors (help-seeking behaviors, knowledge of school and academics) than parents who were less acculturated.

CHAPTER ONE

INTRODUCTION

This year, it is estimated that 11,000 children under the age of 15 will be diagnosed with some form of cancer (American Cancer Society, 2011). Thanks to advances in medical treatment, approximately 80% will survive five years or more – a strong increase from the 1970 survival rate of only 50%. Cancer is still the leading cause of death for this age group, however, and ethnic differences exist not only in survival rate but in health related quality of life for children who have survived cancer. Socioeconomic status (SES) is one of the variables related to survival (Cella et al, 1991). In a study by Bhatia et al. (2002) it was found that while there were no differences in the incidence of central nervous system (CNS) cancers by ethnic group (White, Black, Hispanic, Asian) there were significant differences in overall survival rates among the four groups. Black and Hispanic (Latino) children also had significantly worse outcomes than White and Asian children for those who did survive. Overall, the poor have worse outcomes compared to those who are more affluent (Reynolds, 2003). Disparities could lie in ready access to quality health care, sufficient resources for maintaining compliance with treatment, and other issues related to socioeconomic status and ethnicity. For example, Black and Hispanics tended to continue treatment significantly less often than White and Asian families when compared at a two year follow-up period (Bhatia et al., 2002). The literature is sorely lacking when it comes to this issue, however.

While advancements in medical treatments and modern therapies have contributed to the significant increase in survival rates, patients surviving cancers involving the CNS are at risk of long-term neurocognitive sequelae due to many of the

life-saving treatments received (Nathan, Patel et al., 2007). Many such therapies result in toxic insults to the developing brain and nervous systems, particularly in children with CNS cancers such as acute lymphoblastic leukemia (ALL) and brain tumors.

Neurobehavioral sequelae are one of the most debilitating late effects observed in this group, with far reaching consequences on the trajectory of educational, social, and adaptive development, impacting quality of life (QOL) outcomes well into adulthood (Patel, 2008). Research investigating late effects in pediatric survivors of CNS cancer has revealed greater social, emotional, and behavioral problems compared to those with non-CNS cancer (Fuemmeler, Elkin, & Mullins, 2002). Declines in cognitive functioning not only impact the cancer patient's ability to adapt to the stress of the illness itself; these children also incur significant deficits in academic and social competence as well (Olson, Boyle, Evans, & Zug, 1993).

Additionally, those who are poor, lack health insurance, or have inadequate access to health care resources experience higher cancer incidence and mortality rates (ICC, 2010). Reasons for health disparities can also include socioeconomic status (SES), lack of education, and lack of acculturation. Acculturation is the adopting of behavior patterns of the surrounding culture (Dictionary.com, 2011). Cancer survivor children whose families are less acculturated and therefore cannot or do not access the necessary resources to help their child recover from the after-effects of cancer treatment may therefore be particularly vulnerable to the late effects of cancer. In the United States, the Latino population is the fastest growing minority group, currently comprising 32% of California's population. The term Latino refers to people living in the United States whose origins can be traced to the Spanish-speaking regions of Latin America, including

Mexico, Central American, South America, and the Caribbean (Flores, 2000). This group also has the lowest educational attainment in the country, with only 52% having completed high school and only 9% attending four or more years of college. Furthermore, one out of four Latino families in California lives in poverty (Patel, 2008). Lack of English proficiency is extremely problematic for these individuals, and so may be a population with less optimal acculturation and thus greater vulnerability to childhood late effects in cancer survivors.

Given that Latino children with cancer may represent a particularly vulnerable population, the overall objective of this study was to identify factors that may impact this group's late effects. To this end, we aimed to examine aspects of parenting factors (knowledge, self-efficacy, and pro-learning parenting behaviors) among Latino parents and how these factors impacted the child's neurobehavioral functioning (including academic, cognitive, and behavioral functioning) after treatment for cancer affecting the CNS. Data on the parents' interests, perceived barriers, and preferred format for parenting were also obtained in order to assess how level of acculturation, attitudes, and behaviors toward academic priorities affected the child's neurobehavioral functioning.

Availability of outside support was also taken into consideration. Factors having the greatest potential for improving the child's neurobehavioral outcomes following cancer treatments targeting the CNS, such as cranial irradiation and intrathecal chemotherapy, were investigated. The relationships between parenting factors, child-specific clinical and host variables, and sociocultural variables, including predominant language, SES, and acculturation, were examined as well.

CHAPTER TWO

LITERATURE REVIEW

Childhood Cancer in the United States and Worldwide

Leukemias, central nervous system cancers, and lymphomas account for over half of the pediatric cancer cases reported each year in the United States. Leukemia is the most common form affecting children, accounting for approximately one third of childhood cancers. CNS cancers (brain tumors and other cancers involving the central nervous system) are the second most common, making up nearly 24% of this population, and Lymphomas (tumors of the lymph system) are the third most common form of cancer in children (National Cancer Institute (NCI), 2011). While the majority of children diagnosed with cancer in the United States will survive long term (over 5 years), cancer cure often comes at a high price. Many survivors will face significant late effects as a result of the life saving treatment for this condition. Late effects are the consequence of cancer treatment that appear months or years after treatment has ended, and can include mental and/or physical complications (including secondary cancers) resulting from surgery, chemotherapy, radiation therapy, or other treatment regimens (American Cancer Society, 2010).

What is Cancer?

Cancer is a term used for disease in which there is uncontrolled division of abnormal cells in the body. These cells often invade other tissue via the blood and lymph systems (NCI, 2008). While there are more than 100 types of cancer, these tend to be

grouped into five main types: leukemias (cancers that begin in blood forming tissue such as bone marrow), lymphomas (cancer of the immune system), CNS cancer (cancers that begin in the tissues of the brain and spinal cord), carcinomas (cancers that begin in the skin or in tissues that line or cover internal organs), and sarcomas (cancers that begin in bone, cartilage, muscle, blood vessels, or other connective tissue). Cancers begin at the cellular level, when deoxyribonucleic acid (DNA) becomes damaged or mutated.

Human DNA is packaged in 23 pairs of chromosomes. Chromosomes are strands of DNA, which is the hereditary material found in nearly every cell in the body. It contains the genetic code (instruction) for how the cell functions. Some genes contain instructions for cellular growth and cell division; these are oncogenes. Other cells inhibit this type of growth; these are suppressor genes. It is the mutation (defects) of oncogenes that cause cancer. While some mutations are inherited, others may result from exposure to environmental factors, such as radiation, or immune deficiencies, such as drug treatment or diseases like acquired immune deficiency syndrome (AIDS).

Leukemia

Among the various cancer types found in children, leukemia is the most common form. This is a malignancy of the blood forming tissue, characterized by abnormal proliferation of leukocytes (white blood cells) and/or bone marrow. Clinically and pathologically, leukemia is subdivided into a variety of large groups that include both acute and chronic forms. Leukemias are further subdivided depending on which type of blood cells are affected. Acute lymphoblastic leukemia (ALL) is the most common type in young children, though adults can also acquire the disease.

Causes of this cancer type have been extensively researched. The link between several environmental factors appears to be significant, including ionizing radiation (such as x-rays), pesticides, solvents, and smoking. Ionizing radiation increases chemical activity inside cells and can lead to health risks, including cancer. Certain types of chemotherapy have been linked to development of a second primary cancer in children (NCI, 2011). Children with certain genetic conditions, such as Down syndrome, also appear to have an increased risk for developing leukemia (Ravindranath, 2005; Armstrong, 2006).

Central Nervous System Cancers

CNS cancers are the second most common cancers in children. These can involve the spinal cord as well as the brain, and occur most commonly in younger children (those under seven years of age). Brain cancers appear to be on the rise in the last decade or so (NCI, 2010). While the survival rate has increased due to an improvement in detection and in treatment options, quality of life post-treatment has not improved much for these patients, as the aftereffects from the treatment itself often come at a high price (Rosoff, 2006; Oeffinger et al., 2006; Boman, 2007). Late effects (residual effects that show up months or years after treatment) and other secondary health problems resulting from chemotherapy, radiation, and surgery can range from mild to severe.

Less is known about the cause of CNS cancers in children, though a link between these and ionizing radiation has been established (Gurney, Smith, & Bunin, 1999; Preston-Martin, 1996). Some studies have also suggested a link between the use of some insecticides in the home and brain tumors in small children: homes where certain

pesticides were used found a 70% increase in brain cancer risk in children under five, for example (NRDC, 2010).

Lymphomas

Cancers of the lymph system include two principal types: Hodgkin's disease and non-Hodgkin's lymphoblastic and large cell lymphoma. Non-Hodgkin's lymphoma (NHL) includes several different types, from aggressive (fast growing) to indolent (slow growing), though this cancer type tends to be less common in children under four (NCI, 2008).

Like other forms of childhood cancer, the cause of lymphomas is unknown. Many of these conditions, however, appear to be related to immune system deficiencies. Recent research by Mueller (1999) has shown that children with acquired immunodeficiency syndrome (AIDS) have an increased risk of developing non-Hodgkin's lymphoma and sarcomas (malignant tumors arising from connective tissue such as muscle or bone).

Treatment for Childhood Cancer

Chemotherapy

Chemotherapy is the use of chemical agents to kill cancer cells. There are several types of these agents, and doses vary depending upon certain factors, such as cancer type, tumor location, and resistance to treatment. Method of deliver also varies; the goal is to reach cancerous cells and stop, or at least slow, their growth. It can be administered directly to the bloodstream (intravenously), intrathecally (injected into the spinal or other CNS canal), by intramuscular injection (injected into a muscle), intraperitoneal injection

(injection into the abdominal cavity), subcutaneously (injected under the skin), or orally (ingested in pill or liquid form).

Chemotherapeutic drugs work by inhibiting mitosis (cell division) while others can cause cells to undergo apoptosis (self-programmed cell death). Unfortunately, several of these agents are associated with neurocognitive deficits, including those involving language and attention, delays in age appropriate developmental progress, declines in academic achievement, visual and perceptual motor skills, verbal and nonverbal memory, and decrease in full scale IQ (Bisen-Hersh, Hineline, & Walker, 2011; Lesnik et al., 1998; Copeland et al., 1996; Brown et al., 1998). While research continues to search for ways to ameliorate the negative effects due to such treatments, specific drug impacts are difficult to pinpoint, as treatment often involves the use of several medications in unison (Janzen & Spiegler, 2008; Waber et al., 2000). Methotrexate (MTX) is the cornerstone of treatment for acute lymphoblastic leukemia (ALL) and other cancers, and is the agent most associated with neurocognitive late effects when given intrathecally or intravenously (Kadan-Lottick et al., 2009).

A study by Lesnik et al. (1998) found that children under the age of five years who had been treated intrathecally with MTX displayed significant reductions in visual-spatial attention, visuo-motor organization and coordination, and short-term memory as a result of reductions in the left and right prefrontal association cortices and posterior cerebellar vermis. Risk appears to be most associated with age at administration, dose, route of administration, and schedule. MTX is often administered with cytarabine and corticosteroids; the extent to which these agents are also neurotoxic is still under

investigation, particularly in the role they play in learning deficits (Bisen-Hersh, Hineline, & Walker, 2011).

Cranial Radiation Therapy (CRT)

Cranial radiation therapy (CRT) involves direct radiation to the head. It is intended to prevent cancer from metastasizing (spreading) within the brain. While CRT has been shown to treat patients who are at high risk of neoplastic (new tumor growth) involvement of the nervous system (Gurney, Smith, & Bunin, 1999; Preston-Martin, 1996), it is also associated with some of the most extreme adverse neurocognitive late effects in children, particularly when administered to younger children (those under seven years of age). Those treated with CRT can have declines in IQ by as much as 15 to 25 points compared to those without CRT (Moore, 2004). More recently, CRT has been replaced by intrathecal chemotherapy (ITC) as a form of CNS prophylaxis in hopes of eliminating some of the severe impairments caused by this treatment, but long-term outcomes remain to be seen (Pui et al., 2009).

Complications resulting from CRT are divided into acute (during radiation treatment), early-delayed (two to four months after radiation), and late effects (90 or more days post radiation). Radiation works by damaging the DNA of the cell. An amount of necessary radiation is determined depending upon cancer type (often in the 60 to 80 Gy range) and then the amount is fractionated (spread out over time) at a dose of one radiation treatment per day for five days per week. For children, the typical amount of radiation is reduced from 1.8 to 2 Gy to 1.5 to 1.8 Gy per fractionation in order to reduce some of these toxic effects.

Surgery

Direct injuries to the brain can occur as a consequence of the tumor itself or as a result of neurosurgical insult. Resection (surgical removal) of cancerous tissue via craniotomy is the common approach to dealing with brain tumors. A craniotomy involves removing a flap of bone from the skull in order to access the brain. Surgery to the brain can result in a host of late effects depending upon the type of cancer and the amount of damage in the part of the brain operated on (Castillo, 2008). The objective of neurosurgery is to remove as many tumor cells as possible, thus making chemotherapy and/or radiation more effective, but the amount of healthy tissue that needs to be removed as well as complications after surgery will determine outcomes.

Tumor size and location are also associated with outcomes. Those in the cerebellar hemisphere, for example, often result in difficulties with memory, motor skills, attention, and performance IQ, while those in the posterior fossa are associated with memory and motor problems (Steinlin et al., 2003). Neurosurgical resection may result in positive outcomes (removing the presence of a mass that is infiltrating and harming vital brain structures) or negative ones (leaving lesions that interfere with processing speed and other significant neurocognitive deficits).

Late Effects Resulting From Chemotherapy, CRT, and Surgery

Long after the necessary life saving treatment for cancer has ended, treatments such as chemotherapy, radiation, or the surgery itself often result in late effects. Late effects differ from the side effects that may linger for months or years but then disappear with time. Late effects are lasting, and all too often permanent, effects resulting from

treatment, and can include conditions such as infertility, heart problems, difficulties with memory, and a host of other issues depending upon the type, location, and extent of treatment (Schnoebelen et al., 2008).

Studies have consistently demonstrated that children receiving prophylactic ITC demonstrate below average performance on measures of cognitive and academic abilities compared to controls, especially in younger children. Those receiving cranial irradiation fare much worse, while those receiving both radiation and ITC have shown the highest deficits in areas relating to neurocognitive function (Brown et al., 1998; Raymond-Speden, Tripp, & Lawrence, 2000), with those receiving higher doses showing worse outcomes.

Neurocognitive Late Effects

Research has clearly shown that radiation and chemotherapy cause changes in brain tissue. Neuroimaging studies have revealed that cerebral atrophy, calcifications, white matter lesions, microvascular lesions, demyelination, and breakdown of the blood-brain barrier occurs as a result of such therapies (Mulhern & Palmer, 2001). Diffuse white matter pathology would certainly affect functions associated with regions of the brain dependent upon healthy tissue. White matter is the vital tissue involved in the relay of sensory information. These myelinated tracts are responsible for transmitting and speeding transmission between the cortex and other parts of the brain, thus affecting its function. Lesions and demyelination can result in a multitude of symptoms, depending upon the cells affected. This disruption of signals between the brain and the rest of the body can become problematic, depending upon the extent of the damage itself. Affected

functions could certainly include attention and information processing speed, which would become noticeably impaired after these treatments (Mulhern & Butler, 2004). A separate study by Butler et al. (2008) found that children ($N = 161$) who had undergone CNS malignancy/treatment demonstrated consistent patterns of attentional deficits. Assessments included a battery of neurocognitive instruments, including the Continuous Performance Test (CPT; Conners, 1992) and the Conners' Parent Rating Scale: Long Version—Revised (CRSS: LV–R; Conners, 1997).

A report by the Children's Oncology Group (Nathan, Patel, Dilley et al., 2007) found that 40 to 100% of brain tumor survivors experience neuropsychological dysfunction, with attention and concentration difficulties being particularly common. Difficulties with sustained and/or disrupted attention impact every area of the survivor's life, and academic declines typically become more apparent in children who have treatments involving chemotherapy and irradiation (Copeland, Moore, Francis, Jaffe, & Culbert, 1996; Hewitt, Weiner, & Simone, 2003; Butler & Mulhern, 2005). According to Achanta, Fuss, and Martinez (2009), such deficits may be associated with decreases in hippocampal granule cell proliferation and cell loss. In his study, it was found that rats exposed to whole brain irradiation demonstrated a dose dependent decrease in behaviors related to learning and memory for those tasks dependent upon normal hippocampal function.

Physiological Late Effects

Patients experience increased vulnerability to common illnesses and even secondary cancers as a result of a compromised immune system, particularly for those

treated at younger ages; risk increases significantly for those exposed to radiation at young age and increases with dose of radiation (NCI, 2011). These effects often last well into adulthood. In an article by Casillas, Zebrack, and Zeltzer (2006), patients described the many physiological challenges they faced as adults, many describing effects 20 years after their cancer had been cured. Some expressed grief associated with infertility resulting from treatment, while others reported chronic pain and other health problems, including poor vision, problems with equilibrium, allergies, and short stature. In a report by Oeffinger et al. (2006) on *Chronic Health Conditions in Adult Survivors of Childhood Cancer*, it was found that among 10,397 survivors, 62.3% had at least one chronic condition; 27.5% had a condition that was severe or life threatening. As a group, cancer survivors were found to be eight times more likely than their siblings to suffer from conditions such as secondary cancers, cardiac difficulties, lung and renal disease, seizure disorders, thyroid disease, and severe cognitive dysfunction.

How Environment Impacts the Expression of Late Effects

Home, academic, and community environments may also impact the patient's ability to compensate for deficits caused by cancer treatment. Mulhern and Palmer (2001) state that ethnicity and parental education are among the sociodemographic factors that can account for some of the variance in IQ among healthy samples of pediatric cancer patients. Socioeconomic status (SES) has been positively correlated with lower IQ and other poor neurocognitive outcomes (Copeland, Moore, Francis, Jaffe, & Culbert, 1996; Nathan et al., 2007). In a study by Zeltzer et al. (2008), greater psychological distress and poor health related quality of life (HRQOL) was positively correlated with being female,

having lower education levels, lower SES, poor access to medical care (including lack of medical insurance), and treatment with CRT. Thus, children treated for CNS cancers, and children from low SES immigrant families may be especially vulnerable to neurocognitive late effects such as cognitive and academic achievement deficits (Patel, 2008). Moreover, parents who feel unable to communicate with teachers or doctors often lack the tools (knowledge and self-efficacy) they need in order to access the resources their children need, if indeed they are even aware these exist.

Declines in intellectual functioning in the first few years post treatment are also common. Research has consistently shown that the majority of children who have had cancer treatment will struggle academically on some level, and many will require special education services. While declining academic performance can often be ameliorated by tutoring and special education programs designed to help the child compensate for the loss in aspects of attention, working memory and difficulties in information processing resulting from neuronal damage by the cancer or cancer treatment itself, access to these services varies widely. Not only does this require a high value on education, the ability to provide the necessary support the child needs, and the necessary resources in both the home and school environments, but parents' ability to meet these needs varies. This is where some of the disparities often lie.

Impact of Cancer and Cancer Treatment on Parents

Having a child with cancer is a universally distressing life circumstance for the family. While several factors are related to this issue that may exacerbate or ameliorate it,

the fact is that cancer impacts the entire family (Marshall et al., 2008), and does so on multiple levels.

Family

According to research by Kazak et al. (2005), demographic status such as child's age at diagnosis is not the only predictor of parental distress or psychosocial problems. Rather, it is the long term difficulties that are significantly related to greater parental stress. Many parents suffer post traumatic stress symptoms as a result of their child's illness (Norberg & Boman, 2008; Jurbergs, Long, Ticona, & Phipps, 2009). It has been said that cancer is a family disease that impacts the life course of all members of the family (Chesler & Barbarin, 1986).

The stress of having a child with cancer may be especially difficult for mothers (Marshall et al., 2011). Parents, especially mothers, experience an extremely high level of general anxiety, particularly when the child expresses fear and distress. A study by Zebrack, Chesler, Orbuch, and Parry (2002) found that mothers' worries were significantly related to their perceptions of their child's worries and the meaning they attached to the cancer experience. In other words, if the child experienced substantial crisis and stress, parental distress was higher. This study also emphasized that parental distress lasted much longer than cancer treatment did; fears and concerns for the child's future health, potential for relapse, and psychosocial development were also of grave concern for parents.

SES

Both survivors and parents with lower SES tend to experience the greatest amount of overall stress related to the child's illness. Worries can be as basic as having the necessary health insurance to cover medical costs, or the financial means to get to and from doctor appointments. Parents facing such concerns in addition to the pain and suffering their child is experiencing suffer incredible stress. Fisher (2004) found that SES and membership in an ethnic minority group (especially Hispanic) resulted in greater difficulties in the treatment process itself. Parents in this group found it extremely difficult to understand the informed consent process and to communicate with clinicians. Many of these parents will often display poorer coping skills and experience less desirable psychosocial outcomes. Such stressors often result in marital disharmony and loss of family cohesion, exacerbating an already painful situation. Female caregivers, for example, experience particular burden on multiple levels, and report more anxiety and depression than their male partners (Marshall et al., 2011).

Education

Miller et al. (2005) found that parents with less education had less familiarity with medical terms and scientific concepts, thus complicating the informed consent and treatment process for their child newly diagnosed with cancer. While the experience of cancer differs for subgroups of the population, those who have been shown to be at greater risk for chronic psychological and cognitive adverse effects among survivors of cancer are those who are female, those with a lower SES status, and those with a low education level (Cantrell, 2007). Females struggled with role achievement and self-

efficacy, while survivors overall felt less able to earn a degree and earn sufficient income to support themselves. These individuals can experience impairments that hinder adjustment and quality of life, including psychological or social difficulties, lower levels of self-esteem, physical health, and social support compared to age matched samples. In another study by Cantrell (2011) factors predicting lower HRQOL included education level, household income, employment status, and health insurance issues.

Ethnicity

Factors such as ethnicity and cultural practices, communication styles, socioeconomic status, parent education, and level of psychosocial support all impact the level of distress the family experiences. Cultural preferences for dealing with family difficulties also vary widely; therefore acculturation becomes an issue for those parents who believe that seeking help outside the family is not an acceptable option when it comes to educational or psychological support.

In particular, the Latino culture is collectivistic, typically highly cohesive, and tightly bonded emotionally (Schwartz, 2009; Flores & Vega, 1998). A major emphasis is placed on family as a source of protection against the hardships of life. Such cultural influences will impact the cancer affected families in unique ways. A study by Casillas, Zebrack, and Zeltzer (2006) of 57 childhood Latino (n = 27) and non-Latino (n = 30) cancer survivors found, for example, that there are cultural differences in the way that families dealt with cancer. For Latinos, in which the whole family is included in the cancer experience, the experience resulted in strengthened parent and sibling relationships, while the opposite was true for non-Latinos. On the other hand, while

highly cohesive families often have psychologically favorable outcomes, such as strong intra-family support and lower levels of distress during cancer treatments (Phipps et al., 2005), such families also tend to experience more isolation from outside the family, and therefore lack the support the community can provide (Yi, 2009).

A study by Meeske, Patel, Palmer, Nelson, and Parow (2007) found that ethnic minority status was one of the factors associated with poorer physical functioning, fatigue, and psychosocial functioning in cancer survivors. A later study by Yi (2009) further delineated aspects of ethnicity that may account for some of these ethnic differences in functioning. These authors found that one of the key factors in stress reduction and positive coping was open communication among couples and families about the cancer situation. While there are a wide range of factors that impact parents' willingness or ability to communicate, ethnicity is certainly one factor that influences the interaction behaviors (Flores & Vega, 1998). Moreover, since communication styles are clearly influenced by the family's culture, it follows that utilization of outside resources and availability of social support would also be impacted by these cultural factors. According to Kim, Sherman, and Taylor (2008), culture is what shapes the way individuals obtain and express their needs for support. Positive social support is a key factor in successfully coping with the stress of having a chronically ill child. Thoits (1986) has cited this vital resource as significantly related to positive psychosocial adaptation for both parents and children (including cancer survivor and siblings).

The lack of positive psychosocial adjustment clearly adds to the already difficult situation of trying to help a child recover from cancer. Kovacev and Shute (2011), for instance, reported that acculturation and perceived social support were related to positive

psychosocial adjustment. A study by Marsiglia, Kulis, Garcia-Perez, and Bermudez-Parsai (2011) found that the immigrant population is especially vulnerable to the stress of negative life events. These individuals are exposed to a special set of stressors, including challenges associated with having to learn a new language, becoming familiar with a new culture, inability to find adequate paying jobs, affordable housing, lack of health insurance and/or access to health care, and distance from family and friends. Such stressors leave them vulnerable to isolation, hopelessness, and depression. For some, the acculturation process comes more easily than for others, but it is still a process. Marsiglia et al. found significant negative correlations between hopelessness and three of the predicted variables (positive family support, education, and having a job), especially in the Latinas (females).

Factors That Affect Recovery

SES

Phipps, Rai, Leung, Lensing, and Dunavant (2008) found strong connections between SES and cognitive outcomes (late effects) following cancer treatments. Cognitive and academic outcomes were significantly worse in the low SES group. In a study by Copeland et al. (1996), SES correlated significantly with academic achievement, verbal IQ, perceptual and fine motor skills, executive functioning, and freedom from distractibility. Those in the higher SES groups performed better in every domain.

SES status was found to be an important factor in a study measuring academic achievement in Mexican Americans, who are overrepresented in poverty (Hernandez, 1997, as cited in Aguayo, Herman, Ojeda, & Flores, 2011). Students falling lower on the

SES ladder may not have the same access to educational materials in the home as their more affluent counterparts.

Education

Children who have experienced cancer, particularly CNS cancer and cancer treatment are left with very specialized education needs. Tumor growth impacting learning potential, numerous or lengthy hospital stays, loss of vision, hearing, or other physical impairments affecting fine or gross motor control are among the challenges survivors must face. Additionally, learning difficulties may not become apparent until two to five years after treatment, and the level of difficulty a cancer survivor may experience can vary widely. Accessing special education services may pose difficulties for some parents, particularly when the requirement to obtain such services is a formal written request to a school board to do so.

In a report from the *Children's Oncology Group* (2007), special education interventions such as tutoring and individualized instruction have been shown to result in academic gains for cancer survivors. Not all groups utilize such services equally, however. One factor contributing to this is certainly the education level of the parents themselves; parents who demonstrate pro-learning behaviors (which includes setting a high priority on learning and education) in the home are those most likely to utilize services outside the home for their children. In other words, a more enriched environment may modify the intensity of the effects of treatment, in that it may provide a buffer against the expression of secondary CNS insults caused by treatments.

Ethnicity

For parents struggling with communication due to immigrant status (Latinos, for example, who may not be English proficient), accessing special services for their children becomes especially problematic. Less acculturated parents struggle with the knowledge, education, and resources needed to navigate the often complex educational system and so are often unaware of services available to their children, or may simply be unable to advocate and meet the increased educational needs of their ill child (Patel, 2008).

Parenting Factors

Preliminary results from a pilot study by Patel et al. (in preparation) to identify predictors of cognitive outcomes in 73 childhood cancer survivors from Latino families noted a relatively high prevalence of cognitive and behavioral difficulties, as measured by the Conners Parent Report (see Table 1). Approximately a quarter of the total sample of parents reported cognitive dysfunction (inattention, learning problem, and executive functioning problems) in their cancer survivor child of a magnitude that met criteria for “clinically significant problems,” defined as two standard deviations above the normative mean for healthy children.

Table 1

Cognitive Outcomes Conners

Scale	% of scores $\geq t$ score of 70			% of scores $\geq t$ score of 60		
	Total Leukemia (<i>n</i> = 70)	Brain Tumor (<i>n</i> = 19)	Leukemia (<i>n</i> = 51)	Total (<i>n</i> = 70)	Brain Tumor (<i>n</i> = 19)	(<i>n</i> = 51)
Inattention	27	37	24	50	63	45
Hyper. /impuls	27	26	27	37	37	37
Learning prob	29	37	25	51	53	51
Exec functioning	25	32	22	36	42	34
Aggression	26	21	27	40	42	39
Peer/fam. relations	41	58	35	54	68	49

Note. $p > .05$ for all χ^2 indicating no significant differences in prevalence rates between the two disease groups.

Preliminary results further noted that children with higher dysfunction are at risk for lowered quality of life. Specifically, the investigators conducted ANCOVA to evaluate differences in quality of life, as measured by the PedsQL, between children with higher dysfunction (defined by *t*-scores at or above 60 on the Conners parent report scales) and those with normal functioning (*t*-scores less than 60). Given the profound influence of age at diagnosis on neurocognitive outcomes in childhood cancer survivors,

this variable was used as a covariate in the analyses. Table 2 below shows there were consistently significant differences in quality of life (worse) for those children reported to have problems of a greater magnitude relative to children with fewer difficulties.

Table 2

Correlation Between Parent Factors and Child Outcomes

Conners Scale	QOL means for group with Conners <i>t</i> -scores < 60	QOL means for group with Conners <i>t</i> -scores => 60	<i>F</i> values	<i>p</i> value
Inattention	76.94	61.8	17.63	0
Hyper/Impuls	72.51	63	7.57	0
Learning Prob	76.55	62.12	21.49	0
Executive Fx	76.34	55.57	32.69	0
Aggression	74.93	59.82	17.18	0
Peer/fam rela	76.99	62.61	13.36.	0

Given the quality of life implications for children with poor cognitive and behavioral outcomes following treatment for cancer, it is important to better understand mediators and moderators of these outcomes. There may be protective environmental factors, such as timely intervention and application of remedial resources that may moderate the deleterious effects for more positive functional outcomes over the long term. Within this context, Patel et al. (in prep.) explored in this same sample of 73 Latino families, the relationships between child outcomes and specific parenting factors that prior research indicates play a role in the cognitive and learning performance of school age children.

According to their preliminary results, shown in Table 3, many of the parental behaviors and attitudes measured in this pilot study were not significantly related to child problems or functioning. However, parent efficacy was related to fewer inattention problems and improved scores on the PedsQL. Greater parental knowledge was also related to an improvement in emotional, social, and psychosocial quality of life. They also conducted a median split and separated the 73 parents into a high parental efficacy and low parental efficacy group, and found that parents with greater efficacy have children with fewer problems and better functioning across most of the Conners and PedQL subscales (see Table 4).

Table 3

Correlations Between Parent Behaviors/Beliefs and Child Outcomes

	Pro- learning at School	Pro- learning at Home	Help- seeking	Parent Knowledge	Parent Efficacy
Conners					
Inattention problems	.05	-.09	-.12	-.07	-.21+
Hyperactivity/Impulsivity	.14	-.02	-.06	-.06	-.12
Learning problems	.19	.04	.04	.04	-.12
Executive functioning problems	.03	-.05	-.09	-.06	-.19
Aggression problems	.17	.08	.02	-.04	-.18
Peer/family problems	.22+	-.12	-.05	.05	-.16
PedsQL:					
Physical	-.08	.12	-.11	.07	.12
Emotional	.04	-.01	-.02	.22+	.27*
Social	-.07	.12	-.004	.22+	.31*
School	-.14	.13	-.06	.19	.32*
Psychosocial	-.07	.10	-.03	.26*	.37**
Total	-.08	.11	-.07	.19	.28*

+ $p < .10$; * $p < .05$; ** $p < .01$

Table 4

Mean Conners and PedsQL Scores Between Parents w/ High/Low Efficacy

	High parental efficacy	Low parental efficacy	F	p
Conners				
Inattention problems	57.94	62.79	3.64	.03
Hyperactivity/Impulsivity	58.27	63.41	2.98	.06
Learning problems	60.18	61.77	3.53	.04
Executive functioning problems	55.91	59.21	3.40	.04
Aggression problems	56.18	63.35	3.42	.04
Peer/family problems	61.73	71.47	5.79	.005
PedsQL:				
Physical	70.59	67.91	.62	.54
Emotional	73.38	62.19	2.88	.06
Social	80.51	68.44	2.61	.08
School	66.32	57.5	1.46	.24
Psychosocial	73.35	62.72	3.25	.05

Overall, based on these preliminary exploratory analyses, Latino parents with more knowledge about how to help their child in various domains and self-efficacy had children with better cognitive and behavioral adjustment. Across all of the parenting factors, parental self-efficacy appeared to be most strongly related to child neurocognitive functioning, and parents with greater self-efficacy had children with fewer problems on the Conners and better functioning on the PedsQL. These findings, however, are based

on univariate analyses and by nature, did not incorporate all, or at least the majority, of the predictors that were hypothesized in the study concept to directly, and indirectly, impact child functional outcomes. The objective of this dissertation was to apply more sophisticated statistical analyses to this existing dataset of information from 73 Latino parents and test key hypotheses related to cancer/clinical, socio-demographic, and parenting predictors of child cognitive and behavior outcomes.

Aims and Hypotheses

The goal of this study was to further explore which parenting factors have the greatest influence on neurobehavioral late effects in Latino pediatric cancer survivors using multivariate statistical analyses. To achieve this aim, clinical, sociodemographic, and parenting factors were examined in a Latino sample of 73 parents whose children are at risk for neurobehavioral dysfunction following CNS-involved cancer and/or treatments.

Aim 1. Explore the relationships between Latino parental factors (knowledge, self-efficacy, pro-learning behaviors) and child-specific cognitive and behavioral outcomes, as measured by the Conners Rating Scale (Parent Report Short Version) and the Pediatric Quality of Life scales.

H1: After controlling for any influence of the clinical factors (i.e. type of cancer, cranial radiation, and age at diagnosis), higher parental knowledge, parental-efficacy, and pro-learning parenting behaviors will result in higher cognitive functioning (learning, executive function, attention) and behavioral functioning (HRQOL) in pediatric cancer survivors.

Aim 2. To examine clinical and sociodemographic predictors of parenting factors in Latino parents whose children are at risk for neurobehavioral dysfunction following CNS-involved cancer and/or treatments.

H1: After controlling for any influence of the clinical factors (i.e. type of cancer, cranial radiation, and age at diagnosis), less acculturated Latino parents will have lower knowledge, self-efficacy, and frequency of selected pro-learning parenting behaviors compared to more highly acculturated Latino parents.

CHAPTER THREE

METHOD

Participants

Archival data were used for this study. Participants included 73 Latino predominantly Spanish speaking adult parents or primary caregivers of school age children (ages 6-18 years) who were survivors of leukemia, brain tumors, or non-Hodgkin's lymphoma. The child had to have completed cancer treatment and to be medically cleared to be in school at the time of study enrollment. The parent was the only study participant.

Procedure

This study was approved by the Institutional Review Board (IRB) of the City of Hope Medical Center in Duarte, CA.

A cross-sectional design was used. The sample of invited participants was assessed only one time. Potential participants were identified using databases of patients who had been treated at City of Hope Medical Center and from a community collaborator *Padres Contra El Cancer* (PADRES). The project included partnership with a community organization, PADRES Contra El Cancer (PADRES), a non-profit organization established in 1985 and committed to providing culturally relevant educational and supportive services for Latino children with cancer and their families.

A total of 186 families were identified from the database. From these, 104 were contacted by telephone. Following a telephone invitation by a trained student bilingual Latina researcher, study packets were mailed to the 104 parents for completion. The final

sample consisted of 73 consented Latino parents of childhood cancer survivors, representing a 70% response rate. Follow up calls were made and gift cards of \$35.00 were sent to parents for their participation in the study.

Early in the study feedback was obtained from a professional and parent advisory panel on readability, clarify, and relevance of the items on the parenting questionnaires, especially for Spanish-speaking, low SES respondents. Many items were re-worded as advised by the professional advisory committee. The reading level for these questionnaires was targeted to be at the 3rd grade level. The professional advisory panel consisted of multidisciplinary Latino, bilingual professionals who have extensive or relevant professional experience with Latino childhood cancer patients and their families, and included a pediatric psychologist, pediatric oncologist, the CEO of Padres, a pediatric nurse practitioner, and a pediatric social worker.

The refined and culturally adapted questionnaires were then translated into Spanish using standard translation methodology, and pilot tested with four, including two monolingual Spanish speaking parents of childhood cancer survivors, for further minor edits as needed. Two bilingual research assistants conducted the translation into Spanish and back translation into English, with bilingual members of the advisory panel assisting in quality control of the final translations. The published, standardized measures used in this study are available in Spanish, the only study forms requiring translation were the parenting questionnaires (i.e. PBQ, PKEQ), the Child and Family Information questionnaire, and the study informed consent.

Measures

Conners' Rating Scale-3 (CRS), Parent Report Short version (Conners, 2004)

The CRS contains 45 items that assess behaviors in children 6-18 years of age, is reported by parents or caregivers, and is available in Spanish. Items query behaviors related to *Inattention* (easily distracted, has trouble concentrating), *Hyperactivity/impulsivity* (is restless or overactive), *Executive Functioning* (has trouble organizing tasks or activities), *Learning Problems* (needs extra explanation of instructions), *Aggression* (bullies, threatens, or scares others), and *Peer/family Relations* (has no friends).

Parents rate behaviors on a 0 (never/seldom) to 3 (very often/frequently) scale. Raw scores for each of these subscales are converted to T-scores. Scores above 60 are considered to be elevated, with higher scores indicating greater dysfunction. T-scores above 70 are considered very elevated. This instrument showed strong internal consistency (.96) and good validity. In a study by Helton, Corwyn, Bonner, Brown, & Mulhern (2006), the validity of the Conners parent and teacher rating scales in childhood cancer survivors was explored. Results of the study supported the construct validity of the original factor structure of these instruments for the assessment of cognitive and attentional problems in children treated for central nervous system cancer. Although the instruments were originally based on a sample of healthy school-aged children within the general population, the analyses supported their use as part of neurocognitive and psychosocial assessment battery in identifying the magnitude and prevalence of attentional problems in long-term survivors of childhood cancer experiencing late effects of their treatment. The Conners Teacher Report subscale was also deemed appropriate for

the assessment of attentional and cognitive problems among school-aged children who are long-term survivors of cancer.

PedsQL™ 4.0 – Parent Report (Varni et al., 2001)

The Pediatric Quality of Life Inventory (PedsQL) (Varni et al., 2001) parent report measure normed on a sample of 1,677 families from pediatric healthcare settings, including survivors of childhood cancer, assesses health related quality of life (HRQOL). The PedsQL Psychosocial Summary Scale contains the Emotional (five items), Social (five items), and School (five items) Functioning subscales while the Physical Summary Scale contains the Physical Subscale (eight items) assessing children and adolescents ages 8 to 18. Items include: *feels sad or blue, worries; gets teased by other children, trouble keeping up with schoolwork*. Measured on zero (never a problem) to four (almost always a problem) scale, parents are asked how much of a problem each behavior has been in the past month.

Generic Core Scales on this instrument are multidimensional child self-report and parent proxy-report scales developed as the generic core measure to be integrated with the PedsQL Disease-Specific Modules. It consists of 23 items applicable for healthy school and community populations, as well as pediatric populations with acute and chronic health conditions. Internal consistency reliability for the Total Scale Score (alpha = 0.88 child, 0.90 parent report), Physical Health Summary Score (alpha = 0.80 child, 0.88 parent), and Psychosocial Health Summary Score (alpha = 0.83 child, 0.86 parent) are acceptable for group comparisons. Validity was demonstrated using the known-

groups method, correlations with indicators of morbidity and illness burden, and factor analysis.

Child & Family Information Form

The child and family demographic information form is a study-specific questionnaire querying for demographic data such as patient age, gender, ethnicity, marital status of parents, number and age of siblings, education of parents, parental occupations, history of child's school and special education services, and the child's premorbid developmental history, etc. The information on this form also contains the SES information required to calculate a Hollingshead (1975) SES index. In addition, the parent reports the child's cancer diagnosis, month/year of diagnosis, child's age at diagnosis, relapse history, and basic treatment history (cranial radiation treatment vs. non CRT, bone marrow transplant vs. non-BMT, etc.).

The Bidimensional Acculturation Scale for Hispanics (Marin et al., 1996)

The bi-dimensional acculturation scale for Hispanics (BAS) is a 24 item measure of acculturation that measure three language-related areas. Items on this scale relate to linguistic proficiency and usage of Spanish and English show that the scale works well with Mexican Americans and with Central Americans. Half of the items refer to English use or English-language proficiency, and the other half addresses the same areas as they refer to Spanish use or proficiency. Each of the items is scored on a four-point Likert-type scale with anchors of "almost never" (scored as 1) and "almost always" (scored as 4) for the usage-related questions and "very well" (scored as 4) or "very poorly" (scored as

1) for the linguistic-proficiency items. Questions such as, *How often do you speak in English/Spanish? How often do you think in English/Spanish?* are included on the scale. A score of one indicates low level of acculturation and five a high level, while an average score of 2.5 can be used to dichotomize respondents to lower or high levels of adherence to the specific cultural domain. This measure is available in Spanish and widely used to assess Latino individual's adjustment to living in the United States, with several studies to support discriminative validity and reliability. It takes approximately five minutes to complete.

The BAS has shown high levels of reliability and validity, with an alpha coefficient of .87 for the items in the Hispanic domain and .94 for the items in the non-Hispanic domain. Validity was established using several approaches, including correlations with respondents' generational status ($r = .50$ for the non-Hispanic domain and $-.42$ for the Hispanic domain), length of residence in the United States ($r = .46$ for the non-Hispanic domain and $-.28$ for the Hispanic domain), age of arrival in the United States ($r = -.60$ for the non-Hispanic domain and $.41$ for the Hispanic domain), and respondents' own assessments of their acculturative status ($r = .47$ for the non-Hispanic domain and $-.38$ for the Hispanic domain). The BAS has been used with Latinos of all national backgrounds and all generations. The scale has been useful in providing a comprehensive understanding of Hispanic acculturation in areas as diverse as physical health, mental health, drug and tobacco use, educational achievement, employment, and criminal behavior.

***Parent Behaviors Questionnaire – Revised (PBQ-R second revision:
Patel et al., 2004).***

The PBQ is one of the measures that was revised and adapted for this study following input from the advisory committee. The PBQ-R is based on the Parent Belief and Behaviors Questionnaire (PBQ) which is a Likert scale, parent-report measure developed by Patel et al. (2004) to measure parents' beliefs and participation in "pro-learning" behaviors that are conceptually and empirically associated with cognitive and academic promotion for children. The PBQ included items adapted from checklists assessing parent involvement in intellectual and cultural activities developed by Grolnick and Slowiaczek (1994) and parenting variables used in research studies by the National Center for Education Statistics. Items using existing frameworks of parent involvement measured the level of parental engagement in specific pro-learning behaviors, such as helping with homework, building the child's cognitive skills, having contact with their child's school, and utilizing community resources in an effort to promote their child's cognitive and academic development. The PBQ was administered to a community sample of 121 parents of typical/healthy children between the ages of 6 and 18 years old, and the overall internal reliability coefficient of the measure was $\alpha = .83$. Following administration to the healthy community sample, 17 additional items were added to the PBQ to assess parent knowledge about cancer and its effects on learning and cognitive skills (i.e. cancer late effects knowledge) and parent's belief in their ability to help their child with learning and school success (i.e. parent efficacy). Reliability analysis was conducted on a sample of 56 parents of children with cancer for the original subscales,

plus the two additional subscales, *Cancer* and *Efficacy*, and was found to be generally similar to the community sample ($\alpha = .88$).

A principal components factor analysis with Varimax (orthogonal rotation) of the questionnaire found eight factors. Four of the factors were named: parenting behaviors at *Home*, *parenting behaviors at School*, *parent help-Seeking behaviors*, and *Efficacy* scales. The validity of this measure was explored by examining differences in child's objective IQ scores based on level of pro-learning *parenting behaviors at home* among this sample of 56 families. After restricting the analyses to those children who were older than age three at cancer diagnosis, IQ scores for children with higher levels of parent pro-learning behaviors were significantly higher, approximately 12 points, than for the group with relatively lower levels (Patel et al., under review).

The PBQ was subsequently revised to assess the impact of a NCI-funded pilot intervention to improve parents' knowledge, beliefs, and frequency of pro-learning behaviors on behalf of their cancer survivor child, and is referred as the PBQ-R.

Psychometric data for the revised version are available based on a sample of 44 parents of children with cancer (Cuevas et al., under preparation). It was this PBQ-R that was then adapted for the Spanish speaking/Latino sample which is the version used in the dataset that is the focus of this dissertation (PBQ-2nd revision). The 48 Items on this revised questionnaire are measured on a one to five scale, with one being never, two being one to eleven times/year, three being monthly, four being weekly, and five being daily. It takes approximately five to seven minutes to complete.

Given the adaptation for a Latino sample, a new factor analysis was performed on PBQ- 2nd revision. The FA yielded three main factors, similar to the previous versions of

this measures: parent behaviors at home, parent behaviors at school, and a mix of items that tapped into parents help-seeking behaviors on behalf of their child as well as :relationship building” with their child. This later factor was not as clean a construct as the other two factors.

Parent Knowledge and Efficacy Questionnaire (PKEQ).

During the PBQ adaptation for use in an intervention study that targeted parent’s knowledge, beliefs, and pro-learning behaviors, items which were intended conceptually to target knowledge and beliefs were separated into a 2nd form and referred to as the PKEQ. The items from the PKEQ were edited following the Latino advisory committee and are now referred to as PKEQ-R. The questionnaire evaluates the parent/caregiver’s knowledge of specific learning techniques and strategies, behavioral modification principals, and general factors that contribute toward positive school achievement. A factor analyses was conducted on the PKEQ-R using the sample of 73 Latino parents. Five empirically-derived factors emerged: *parent knowledge of cognitive learning processes*, Cronbach’s alpha = .90, *parent knowledge of school and academics*, alpha = .86, *parent knowledge of social skills*, alpha = .90, *parent ability to successfully help their child*, alpha = .84, and *parent knowledge of cancer late effects*, alpha = .66. These measures are described below:

Knowledge of cognitive learning processes items evaluate the caregiver’s knowledge of specific learning techniques and strategies, behavioral modification principals, and general factors that help with positive school achievement. Questions include, *How much do you know about study strategies that may help your child with*

academic skills? How much do you know how to increase your child's persistence in learning and school work?

Knowledge of school and academics items evaluate the caregiver's belief in their personal ability to help their child with learning and school. These items include: *I am able to help my child learn; I feel successful in my efforts to help child learn; I have enough time and energy to supervise child's homework; I know how to help my child make good grades*).

Knowledge of Social Skills evaluates the caregiver's belief in their personal knowledge of helping their child with peer interactions. Items include knowing about such things as, *How to find resources within the community to help your child; How to improve your child's socialization skills*.

Ability to Successfully Help Child evaluates the caregiver's belief in personal ability to help the child academically. Items include: *I am comfortable with talking with my child's primary teacher about my child's needs and problem areas; I know how to use study strategies to help my child with reading comprehension, writing, and other academic skills*.

Knowledge of Cancer-related Late Effects evaluates the caregiver's belief in their knowledge of the child's learning needs related to the cancer illness (i.e. late effects). Items question the caregiver's knowledge about school and learning needs of children diagnosed with cancer with items such as: *How have your child's school and learning experiences been negatively affected by cancer since s/he completed treatment?*.

All items in the questionnaire are rated on a one (no knowledge) to five (a lot of knowledge) scale, in the area queried.

Since some of the items that loaded on the same factor did not appear to have strong face-validity, as they appeared to measure different concepts, the primary author developed two conceptually-derived scales/factors for PKEQ-R2. Specifically, all questionnaire items designed to assess parent knowledge of how to help their child in various domains were grouped together and labeled as the “Parent knowledge” scale, and all of the items designed to assess parent’s belief and confidence in their ability to help their child in various areas were grouped and labeled as “Parent Efficacy.” Hence, there are both empirically-derived and conceptually-derived parenting factors that will be investigated in the current project.

CHAPTER FOUR

RESULTS

Statistical Analyses

First, a hierarchical regression was conducted to control for any influence of the clinical factors (i.e. type of cancer, cranial radiation, and age at diagnosis), parenting factors (parent SES, education, acculturation, parental knowledge, self-efficacy, and pro-learning parenting behaviors) and how these would impact child cognitive functioning (learning, executive function, attention) in pediatric cancer survivors. Next, a variety of statistical methods were used to test the hypotheses, including linear regression analysis, ANCOVA, independent samples *t* tests, and structural equation modeling. Composite scores and subscales were used for hypothesis testing. Data were analyzed using SPSS version 17.0 and EQS version 6.1 (Bentler, 1995).

Participants

Participants included 73 Latino parents (13 fathers, 54 mothers, 5 other) of school-aged children who were survivors of cancer involving the central nervous system. The majority of the children's mothers (83%) and fathers (85%) were born outside the US. Some (29%) of the mothers and 92% of the fathers were currently employed. For 77% of the families, Spanish was the primary language spoken in the home (see Table 5). Cancer survivor children ranged in age from 6 to 18 years ($M = 11.63$, $SD = 4.40$). The majority of the children ($n = 51$) were diagnosed with leukemia, 19 had brain tumors, and three had non-Hodgkin's lymphoma. For most of the children (76%) it had been three or more years since they completed cancer treatment. Treatments included chemotherapy

(92%), surgery (43%), bone marrow transplants (22%), radiation (21%), and radiation involving the brain (14%) (see Table 6).

Table 5

Parent Demographics

	Overall <i>N</i>	Overall %
Parent respondent		
Male	13	.18
Female	56	.77
Unstated	4	.05
Language spoken		
Spanish	56	.78
English	17	.23
Married	49	.67
Born outside U.S.		
Father	62	.85
Mother	61	.83
Education		
Fathers:		
High School graduate	9	.29
Mothers:		
High School graduate	14	.25
Family Income		
< 10,000	13	.19
10 – 19,000	20	.29
20 – 49,000	31	.43
50 - 74,000	6	.09
Currently employed		
Father	51	.70
Mother	21	.29

Table 6

Survivor Sample Characteristics

	<i>N</i>	%
Age at diagnosis		
< 7 years	12	.16
8-12	26	.36
13-18	35	.48
Diagnosis		
Leukemia	51	.71
Brain tumor	19	.26
NHL	3	.03
Time since last treatment		
> 3 years	67	.92
Relapse	4	.06
Treatment received		
Chemotherapy	67	.92
Craniospinal Radiation	15	.21
Surgery	31	.43
Cranial Radiation	10	.14
Bone Marrow Transplant	16	.22
Problems/Difficulties		
Vision	21	.29
Blurred vision	11	.15
Hearing	8	.11
Balance	10	.14
Speech	5	.07
Academic problems	39	.53

Measures of Child's Cognitive Outcomes

Hierarchical Regression analyses were conducted for each child cognitive outcome with disease factors (age at diagnosis, cancer diagnosis, CNS radiation treatment) entered in Step 1, parent demographic factors (income level, mother education, acculturation,) entered in the Step 2, and parenting attitudes and behaviors (pro-learning behaviors at school, pro-learning behaviors at home, and help-seeking behaviors from the PBQ, and parental knowledge and efficacy items from the PKEQ) entered in Step 3. Results are displayed in Tables 7 through 10.

Overall conclusion The attention and learning outcomes are mainly predicted by younger age at diagnosis, but were not strongly predicted by the parenting factors. Learning problems, aggression, and peers/family problems seem to be related to more parental pro-learning behaviors at school.

Table 7

Hierarchical Regression (DV: Conners Inattention Problems)

	Model	B	SE	Beta	t	Sig.
1	(Constant)	68.68	4.72		14.56	.000
	age of diagnosis	-1.15	.57	-.26	-2.00	.05
	radiation brain	3.84	5.54	.09	.69	.49
	Diagnosis: (Leukemia or other)	-5.61	4.37	-.17	-1.28	.21
	$R^2 = .11, F(3,54) = 2.18, p = .11$					
2	(Constant)	72.42	8.42		8.60	.000
	age of diagnosis	-.95	.59	-.21	-1.61	.11
	radiation brain	4.96	5.58	.12	.89	.38
	Diagnosis: (Leukemia or other)	-5.48	4.60	-.17	-1.19	.24
	annual income range	1.41	2.40	.08	.59	.56
	mother's education	-1.41	1.70	-.15	-.83	.41
	BAS non-Hisp	-1.69	2.67	-.12	-.63	.53
	$R^2 = .16, F(6,51) = 1.60, p = .17,$ $\Delta R^2 = .06, \Delta F = 1.01, p = .39$					
3	(Constant)	98.83	15.75		6.28	.000
	age of diagnosis	-1.06	.66	-.24	-1.60	.12
	radiation brain	4.45	5.44	.11	.82	.42
	Diagnosis: (Leukemia or other)	-3.92	4.14	-.12	-.95	.35
	annual income range	1.11	2.15	.06	.516	.61
	mother's education	-.06	1.57	-.01	-.04	.97
	BAS non-Hisp	-3.34	2.65	-.23	-1.26	.21
	PBQ pro-learning behaviors at school	1.95	2.84	.11	.69	.49
	PBQ pro-learning behaviors at home	-5.09	3.50	-.24	-1.45	.15
	PBQ help-seeking	-.95	3.13	-.05	-.30	.76
	PKEQ social	-1.21	2.95	-.07	-.41	.68
	PKEQ school	3.92	3.80	.19	1.03	.31
	PKEQ cognitive	-1.83	3.84	-.10	-.48	.64
	PKEQ success	-8.11	3.65	-.42	-2.22	.03
	PKEQ cancer	5.44	2.14	.34	2.54	.01
	$R^2 = .46, F(14.43) = 2.65, p = .007,$ $\Delta R^2 = .29, \Delta F = 3.05, p = .008$					

Table 8

Hierarchical Regression (DV: Conners Learning Problems)

	Model	B	SE	Beta	t	Sig.
1	(Constant)	68.09	4.46		15.27	.000
	age of diagnosis	-1.20	.54	-.29	-2.22	.03
	radiation brain	3.13	5.24	.08	.60	.55
	Diagnosis: (Leukemia or other)	-2.97	4.13	-.10	-.72	.48
	$R^2 = .10, F(3,54) = 1.96, p = .13$					
2	(Constant)	73.61	7.85		9.38	.000
	age of diagnosis	-.96	.55	-.23	-1.76	.09
	radiation brain	4.09	5.20	.11	.79	.44
	Diagnosis: (Leukemia or other)	-2.24	4.29	-.07	-.52	.60
	annual income range	.34	2.24	.02	.15	.88
	mother's education	-2.36	1.58	-.27	-1.49	.14
	total BAS non-Hisp	-.35	2.49	-.03	-.14	.89
	$R^2 = .17, F(6,51) = 1.79, p = .12$					
	$\Delta R^2 = .08, \Delta F = 1.55, p = .21$					
3	(Constant)	68.34	15.18		4.50	.000
	age of diagnosis	-.30	.638	-.07	-.48	.64
	radiation brain	3.4	5.24	.09	.66	.51
	Diagnosis: (Leukemia or other)	-2.29	3.99	-.07	-.57	.57
	annual income range	.53	2.07	.03	.26	.80
	mother's education	-2.09	1.51	-.24	-1.38	.17
	total BAS non-Hisp	-1.75	2.55	-.12	-.67	.51
	PBQ pro-learning behaviors at school	5.02	2.74	.30	1.83	.07
	PBQ pro-learning behaviors at home	-2.08	3.38	-.11	-.62	.54
	PBQ parental help-seeking	-1.70	3.02	-.10	-.57	.57
	PKEQ social	-2.55	2.84	-.17	-.90	.37
	PKEQ school	4.48	3.66	.23	1.22	.23
	PKEQ cognitive	2.66	3.70	.16	.72	.48
	PKEQ successfully	-6.73	3.52	-.37	-1.91	.06
	PKEQ cancer	3.37	2.06	.23	1.63	.11
	$R^2 = .44, F(14,43) = 2.37, p = .015$					
	$\Delta R^2 = .26, \Delta F = 2.50, p = .025$					

Table 9

Hierarchical Regression (DV: Conners Aggression Problems)

	Model	B	SE	Beta	t	Sig.
1	(Constant)	64.26	5.39		11.92	.000
	age of diagnosis	-.86	.66	-.18	-1.31	.19
	radiation involving brain	1.74	6.33	.04	.28	.78
	Diagnosis: (Leukemia or other)	.32	4.99	.01	.06	.95
	$R^2 = .03, F(3,54) = .57, p = .63$					
2	(Constant)	71.32	9.51		7.50	.000
	age of diagnosis	-.60	.66	-.12	-.90	.37
	radiation involving brain	3.35	6.30	.07	.53	.59
	Diagnosis: Dichotomous (Leukemia or other)	-.12	5.19	-.00	-.02	.98
	annual income range	1.48	2.71	.08	.55	.59
	mother's education	-1.30	1.91	-.13	-.68	.50
	total BAS non-Hispanic	-3.23	3.01	-.20	-1.07	.29
	$R^2 = .11, F(6,51) = 1.03, p = .42$					
	$\Delta R^2 = .08, \Delta F = 1.47, p = .23$					
3	(Constant)	67.53	17.92		3.77	.000
	age of diagnosis	-.41	.75	-.09	-.55	.58
	radiation involving brain	6.29	6.18	.14	1.02	.32
	Diagnosis: Dichotomous (Leukemia or other)	.88	4.71	.02	.19	.85
	annual income range	1.74	2.45	.09	.71	.48
	mother's education	-1.06	1.78	-.10	-.59	.56
	total BAS non-Hispanic	-2.37	3.01	-.15	-.79	.44
	PBQ pro-learning at school	8.28	3.23	.42	2.56	.01
	PBQ pro-learning at home	.32	3.98	.01	.08	.94
	PBQ parental help-seeking	-1.78	3.56	-.09	-.50	.62
	PKEQ social	-3.25	3.35	-.18	-.97	.34
	PKEQ school	-5.91	4.32	-.27	-1.37	.18
	PKEQ cognitive	1.41	4.37	.07	.32	.75
	PKEQ successfully	-3.03	4.15	-.14	-.73	.47
	PKEQ cancer	5.12	2.44	.29	2.10	.04
	$R^2 = .42, F(14,43) = 2.24, p = .022$					
	$\Delta R^2 = .31, \Delta F = 2.92, p = .011$					

Table 10

Hierarchical Regression (DV: Conners Peer/Family Relation Problems)

	Model	B	SE	Beta	t	Sig.
1	(Constant)	74.67	5.48		13.64	.000
	age of diagnosis	-1.13	.67	-.22	-1.70	.09
	radiation involving brain	6.99	6.43	.15	1.09	.28
	Diagnosis: (Leukemia or other)	-6.40	5.07	-.17	-1.26	.21
	$R^2 = .10$, $F(3,54) = 2.08$, $p = .11$					
2	(Constant)	83.83	8.94		9.38	.000
	age of diagnosis	-.76	.62	-.15	-1.22	.23
	radiation involving brain	9.81	5.93	.20	1.65	.10
	Diagnosis: Dichotomous (Leukemia or other)	-7.88	4.88	-.21	-1.61	.11
	annual income range	3.78	2.55	.19	1.48	.14
	mother's education	-.90	1.80	-.08	-.50	.62
	total BAS non-Hispanic orientation	-6.94	2.83	-.41	-2.45	.02
	$R^2 = .21$, $F(6,51) = 3.52$, $p = .005$, $\Delta R^2 = .19$, $\Delta F = 4.56$, $p = .007$					
3	(Constant)	84.12	15.90		5.29	.000
	age of diagnosis	-.37	.67	-.07	-.56	.58
	radiation involving brain	13.92	5.49	.29	2.54	.02
	Diagnosis: Dichotomous (Leukemia or other)	-6.80	4.19	-.18	-1.62	.11
	annual income range	4.55	2.17	.22	2.10	.04
	mother's education	-.67	1.58	-.06	-.43	.67
	total BAS non-Hispanic cultural orientation	-7.25	2.68	-.43	-2.71	.01
	PBQ pro-learning behaviors at school	9.02	2.87	.44	3.15	.003
	PBQ pro-learning behaviors at home	-6.50	3.54	-.27	-1.84	.07
	PBQ parental help-seek	-2.14	3.16	-.10	-.68	.50
	PKEQ social	-2.27	2.97	-.12	-.76	.45
	PKEQ school	.51	3.84	.02	.13	.89
	PKEQ cognitive	5.75	3.88	.28	1.48	.15
	PKEQ successfully	-6.68	3.68	-.30	-1.81	.08
	PKEQ cancer	3.03	2.16	.16	1.40	.17
	$R^2 = .59$, $F(14,43) = 4.45$, $p = .001$, $\Delta R^2 = .30$, $\Delta F = 3.93$, $p = .001$					

Findings Related to Hypothesis One

Structural equation modeling (SEM) analysis was used to test the hypothesis that parental efficacy would result in higher neurobehavioral functioning in cancer survivor children (H1). SEM was chosen as the best method as it allows for the examination of several variables of interest at once and can be used to test for direct and indirect effects of intervening variables, better model visualization through its graphical modeling interface, the desirability of testing models overall rather than coefficients individually, and the desirability of its strategy of comparing alternative models to assess relative model fit. While reporting SEM results varies widely among researchers, standard reporting conventions developed by the American Psychological Association (2002) and by McDonald and Ho (2002) have been used as a guide.

Methods for specifically evaluating power in structural equation modeling have been developed by several individuals. Those originally proposed by Satorra and Saris (1985) would be tedious to carry out in practice, but more recently, Satorra (1989) recognized that the Wald test (in EQS) could be used to assess the power of an estimated parameter in the model against a null hypothesis. This power-based approach to model modification was advocated by Kaplan (1990), and was used in this paper.

Chi square (χ^2), Comparative Fit Index (CFI) and Root Mean Square Error of Approximation (RMSEA) fit indices were used to assess the overall fit of the model to the data. Generally, acceptable fit is indicated by a non-significant chi-square value (i.e., $p > .05$), with smaller chi-square values (and larger p values) indicating a better fit to the data, CFI values greater than .90, and RMSEA values less than .08 (Tabachnick & Fidell, 2001). The cut-off used for adequate fit for CFI was $>.95$ (Hu & Bentler, 1995) and for

RMSEA was .05 to .08. While the total number of participants ($N = 73$) was somewhat small, previous research has demonstrated that samples fewer than 100 are adequate to conduct SEM (MacCallum & Austin, 2000). According to Ullman (2007), SEM allows for estimation of models with as few as 60 participants (Bentler & Yuan, 1999). Data were cleaned and screened, and cases with missing variables were omitted.

A conceptual SEM model grounded in theory and past research was first created to explore the relationships between parenting factors in Latinos and child neurobehavioral outcomes (late effects). The variables shown on the left side of the figure below (disease and cancer treatment factors, age at diagnosis, age at treatment, and how these impact child outcomes) have been extensively researched in the literature; there still remain gaps in the literature, however, concerning those variables on the right side (parent SES, acculturation, etc.) and related parenting factors that could have an impact on Latino cancer survivor child's neurobehavioral outcomes (see Figure 1).

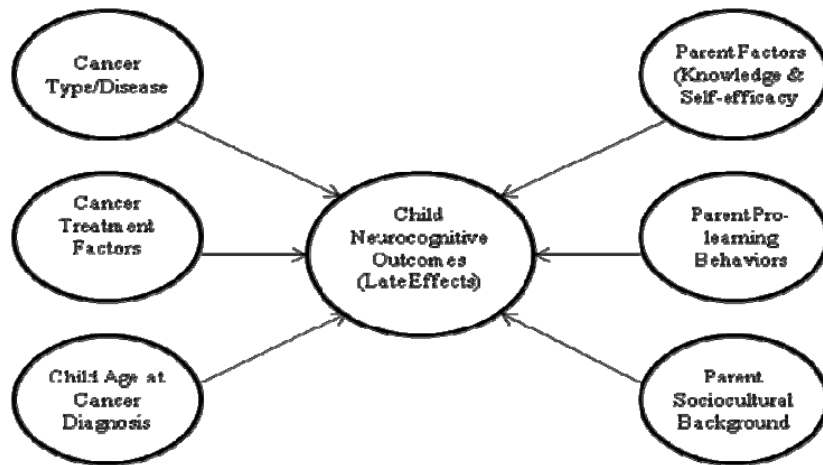


Figure 1. Conceptual Model of the relationship between child cognitive outcomes (late effects) and factors contributing to late effects. Which parenting factors, in addition to disease, cancer treatment, and age have the greatest impact on neurobehavioral late effects in Latino children?

SEM was chosen as an appropriate technique as it allowed for developing a more complex model examining the interrelationships between variables (parent factors, child neurocognitive outcomes (late effects) and child HRQOL).

The hypothesized model examined predictor of Parental Factors, a latent variable measured by the Parental Knowledge and Efficacy Questionnaire (PKEQ) and the Parent Behavior Questionnaire (PBQ), and the outcome variables, a latent variable of neurobehavioral late effects measured by the Conners Parent Report questionnaire, and health related quality of life (HRQOL), a latent variable measured by the items on the PedsQL.

Predictor variables: The PKEQ includes factor analyses-derived five subscales (*parent ability to successfully help child, parent knowledge of school and academics, parent knowledge of cancer, parent social skills knowledge, and parent knowledge of*

cognitive processes). The PBQ includes three FA-derived subscales (*parent pro-learning behavior at home, pro-learning behavior at school, and help-seeking & relationship building behaviors*).

Outcome variables: The Conners includes six subscales (*problems with inattention, executive function, learning, hyperactivity, peer relationships, aggression*).

Only inattention, executive function, learning, aggression, and peer/family relationships were significantly correlated with any of the predictor variables. The PedsQL includes six subscales (*emotional, school, social, physical, psychosocial, and total/overall quality of life*). Only emotional, social, school, psychosocial, and total subscales were significantly correlated with any of the predictor variables. None of the outcome variables were significantly correlated with any of the predictor variables on the PBQ (see Tables 11).

Table 11

Correlation Matrix Hypothetical Model Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1.PKEQ social	-																
2.PKEQ school	.327**	-															
3.PKEQ cognitive	.660**	.318**	-														
4.PKEQ successfully	.517**	.536**	.515**	-													
5.PKEQ cancer	.305*	.255*	.440**	.266*	-												
6.Connors inattention	-0.166	0.016	-0.077	-.331**	0.183	-											
7.Connors hyperactivity	-0.165	-0.006	-0.066	-0.153	0.22	.653**	-										
8.Connors learning	-0.141	0.054	0.08	-0.206	.250*	.779**	.516**	-									
9.Connors exec fx	-0.13	-0.05	-0.051	-.246*	0.061	.720**	.541**	.656**	-								
10.Connors aggression	-0.137	-0.07	-0.061	-.241*	0.23	.643**	.653**	.548**	.570**	-							
11.Connors peer/fam	-0.082	-0.023	0.085	-.262*	0.158	.709**	.496**	.642**	.582**	.617**	-						
12.PEDSQL physical	0.103	0.022	0.064	0.152	-0.022	-.410**	-0.174	-.449**	-.448**	-.288*	-.469**	-					
13.PEDSQL emotional	.242*	0.14	0.208	.265*	0.064	-.440**	-0.233	-.253*	-.409**	-.426**	-.326**	.466**	-				
14.PEDSQL social	.365**	0.142	0.126	.391**	-0.058	-.421**	-0.178	-.463**	-.518**	-.353**	-.598**	.652**	.474**	-			
15.PEDSQL school	0.207	0.127	0.213	.403**	-0.018	-.669**	-.342**	-.539**	-.605**	-.455**	-.521**	.642**	.499**	.649**	-		

Table 11. *Continued.*

16.PEDSQL psychosocial	.333**	0.164	0.219	.432**	-0.006	-.613**	-.300*	-.508**	-.613**	-.494**	-.586**	.707**	.780**	.858**	.860**	-	
17.PEDSQL total	.256*	0.114	0.165	.341**	-0.02	-.572**	-.270*	-.523**	-.591**	-.444**	-.582**	.893**	.704**	.836**	.830**	.949**	-

Correlations PKEQ and CRS

***Correlation significant at the .01 level*

**Correlation significant at the .05 level*

PKEQ: Parent Knowledge and Efficacy Questionnaire

A correlation matrix was then created using only the significantly correlated variables from the parental knowledge and efficacy questionnaire (PKEQ), the Conners Parent Report of executive function scale (CRS), and the Pediatric Quality of Life questionnaire (PedsQL) (see Table 12).

Proposed Structural Equation Model One

The items in Table 12 were those included in the hypothesized model and make up the three latent factors of the model (see Figure 2). Latent constructs are represented by circles, and measured variables are represented by rectangular boxes. Arrows indicate the expectation of a hypothesized effect. Factors are described below:

Factor 1: Parenting Factor, a latent factor, was defined by three factors from the PKEQ (*parent ability to successfully help child, parental social skills knowledge, parent knowledge of cancer related effects*).

Factor 2: Late Effects, a latent factor, was defined by five scales from the CRS, and included *problems with inattention, learning problems, executive functioning, aggression, and peer/family problems* items.

Factor 3: HRQOL, a latent factor, was defined by five scales from the PedsQL scale; *child emotional quality of life, social quality of life, school quality of life, psychosocial quality of life, and overall (total) quality of life*.

Table 12

Correlation Matrix Final Model One Items

	1	2	3	4	5	6	7	8	9	10	11	12	13
PKEQ social	-												
PKEQ success	.517**	-											
PKEQ cancer	.305*	.266*	-										
Conners inattention	-.166	-.331**	.183	-									
Conners learning	-.141	-.206	.250*	.779**	-								
Conners executive	-.130	-.246*	.061	.720**	.656**	-							
Conners aggression	-.137	-.241*	.230	.643**	.548**	.570**	-						
Conners peer/fam	-.082	-.262*	.158	.709**	.642**	.582**	.617**	-					
PEDSQL emotional	.242*	.265*	.064	-.440**	-.253*	-.409**	-.426**	-.326**	-				
PEDSQL social	.365**	.391**	-.058	-.421**	-.463**	-.518**	-.353**	-.598**	.474**	-			
PEDSQL school	.207	.403**	-.018	-.669**	-.539**	-.605**	-.455**	-.521**	.499**	.649**	-		
PEDSQL psych	.333**	.432**	-.006	-.613**	-.508**	-.613**	-.494**	-.586**	.780**	.858**	.860**	-	
PEDSQL total	.256*	.341**	-.020	-.572**	-.523**	-.591**	-.444**	-.582**	.704**	.836**	.830**	.949**	-

**Correlation significant at the .01 level

*Correlation significant at the .05 level

PKEQ: Parent Knowledge and Efficacy Questionnaire; PedsQL: Pediatric Quality of Life scale.

Assumptions

Assumptions (theoretical basis for model specification, univariate and multivariate normality, model identification and fit, etc.) were evaluated through SPSS

and EQS. Byrne (2006) and Hooper, Coughlan, and Mullen (2008) were used as guides for determining whether model assumptions were satisfied. There were thirteen variables of interest included in the hypothesized model. There were no univariate or multivariate outliers.

Structural Equation Model Analysis

It was hypothesized that cognitive and behavioral late effects, a latent variable with five indicators (*problems with inattention, problems with learning, problems with executive function, problems with aggression, problems with peer/family relationships*), and child health related quality of life, a latent variable with five indicators (*emotional well being, school well being, social well being, psychosocial well being, and overall well being*), were directly predicted by parenting factors (*ability to successfully help child, social skills knowledge, knowledge of cancer related effects*) (see Figure 2).

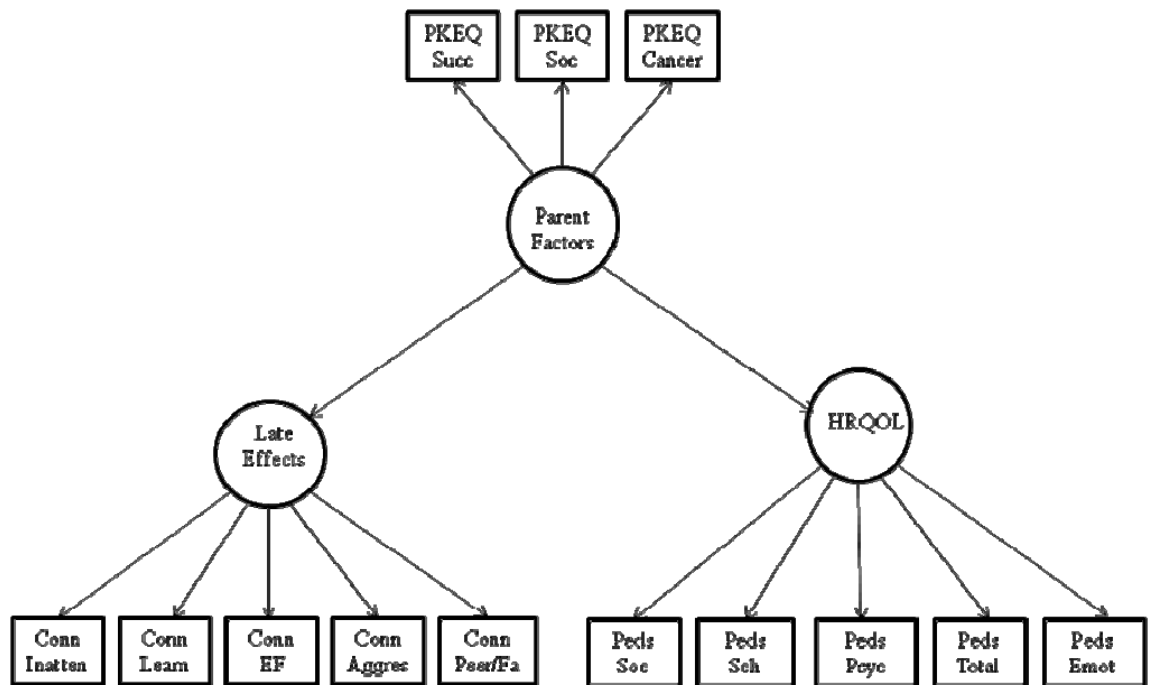


Figure 2. Hypothesized Model of the relationship between (F1) Parent Factors, (F2) Late Effects, and (F3) HRQOL.

An attempt was made to run the model as hypothesized (see Figure 2), but reliable parameter estimates could not be obtained using the original configuration, $\chi^2 = 477.55(63, n = 73), p = .001$, CFI = .57, RMSEA = .34. Multiple steps were followed in the model re-evaluation process. Using parameter estimates, residual covariance matrices, and fit indices of the model as a whole, model modifications were then performed to fit the model, and a better fitting, more parsimonious final model resulted. Specifically, one indicator on Factor One was dropped (parent knowledge of cancer processes, two indicators on Factor Two were dropped (aggression and peer/family items) and three indicators on Factor Three were dropped (emotional, psychosocial, and overall well being). When examining the first hypothesis, it was found that parent factors (knowledge and self-efficacy) did not directly predict child neurobehavioral outcomes (late effects) as

hypothesized. Rather, parent knowledge and self-efficacy more directly predicted child's health related quality of life (HRQOL) (standardized coefficient = .49, $p < .05$, $R^2 = .24$) which in turn predicted of late effects (standardized coefficient = -.74, $p < .05$, $R^2 = .55$) in this sample. The final model fit the data well, $\chi^2 = 15.33(12, n = 68)$, $p = .22$, CFI = .98, RMSEA = .06. All testable pathways were statistically significant. The final model with standardized coefficients can be seen in Figure 3.

Parent Factors, a latent factor, was well defined by each of its measured variables: *Parent ability to successfully help their child* (fixed = .921, $p < .05$; *Parent knowledge of social skills* (standardized coefficient = .55, $t = 2.29$, $p < .05$).

HRQOL, a latent factor, was well defined by each of its measured variables: *School quality of life* (standardized coefficient = .917, $t = 5.50$, $p < .05$); *Social quality of life* (fixed = .702, $p < .05$).

Late Effects, a latent factor, was also well defined by each of its measured variables: *problems with inattention* (fixed = .930, $t = 2.14$, $p < .05$); *problems with learning* (standardized coefficient = .847, $t = 3.98$, $p < .05$), *problems in executive function* (standardized coefficient = .745, $t = 4.94$, $p < .05$).

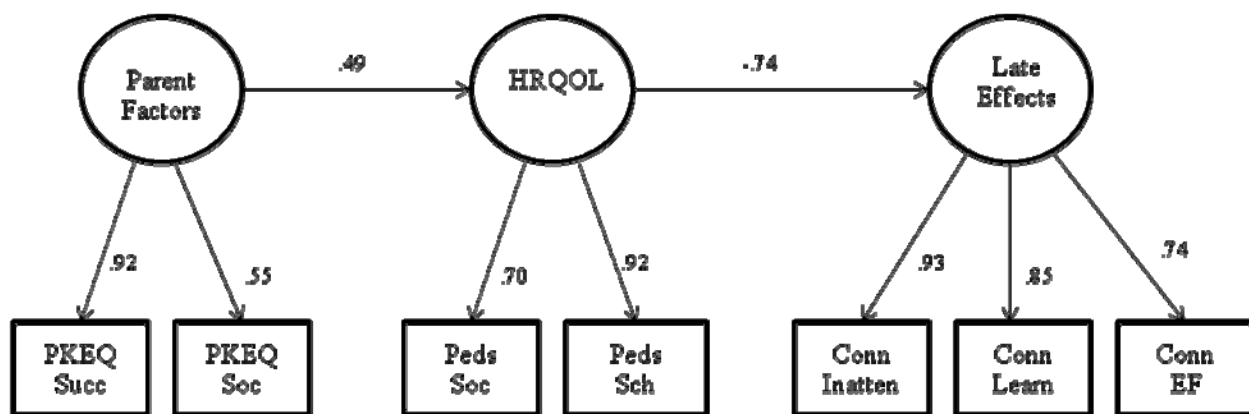


Figure 3. Final SEM of the relationship between Parent Factors, HRQOL and Late Effects. Child social and school quality of life (HRQOL) moderated the relationship between parenting factors (parent ability to help their child succeed (self-efficacy), parent knowledge of social interactions) and cognitive late effects (problems with inattention, learning, and executive function). All testable pathways were statistically significant ($p < .05$).

Findings Related to Hypothesis Two

The hypothesis that less acculturated Latino parents would have lower knowledge, efficacy, and frequency of pro-learning parenting behaviors compared to more highly acculturated Latino parents was also explored using structural equation modeling.

Proposed SEM Model Two

A structural equation model was used to explore the impact of acculturation on parent pro-learning behaviors and child outcomes. The model was constructed using low vs. high acculturation as the independent variable and parent behaviors and child outcomes as the dependent variables. Significantly correlated items in Table 13 are those included in the hypothesized Acculturation model. Path coefficients were examined and

no special problems were encountered during optimization of the model. The model fit the data well, $\chi^2 = 20.33(17 \text{ } n = 68), p = .26$, CFI = .97, RMSEA = .05. All testable pathways were statistically significant (see Figure 4).

Table 13

Correlation Between BAS, PBQ, and CRS

	1	2	3	4	5	6	7	8	9	10	11
1.BAS non-Hispanic	-										
2.BAS Hispanic	.513**	-									
3.PBQ pro-learn school	.067	-.127	-								
4.PBQ pro-learn home	.076	-.073	.462**	-							
5.PBQ parental help-seeking	.244*	-.152	.416**	.445**	-						
6.Conners inattention	-.094	.160	.053	-.091	-.116	-					
7.Conners hyperactivity	-.110	.279*	.138	-.023	-.057	.653**	-				
8.Conners learning	-.124	.129	.187	.039	.043	.779**	.516**	-			
9.Conners exec function	-.168	.150	.033	-.054	-.091	.720**	.541**	.656**	-		
10.Conners aggression	-.241*	.265*	.174	.076	.023	.643**	.653**	.548**	.570**	-	
11.Conners peer/family	-.303*	.239*	.221	-.119	-.054	.709**	.496**	.642**	.582**	.617**	-

**Correlation significant at the .01 level

*Correlation significant at the .05 level

BAS: Bidimensional Acculturation Scale; PBQ: Parent Behavior Questionnaire.

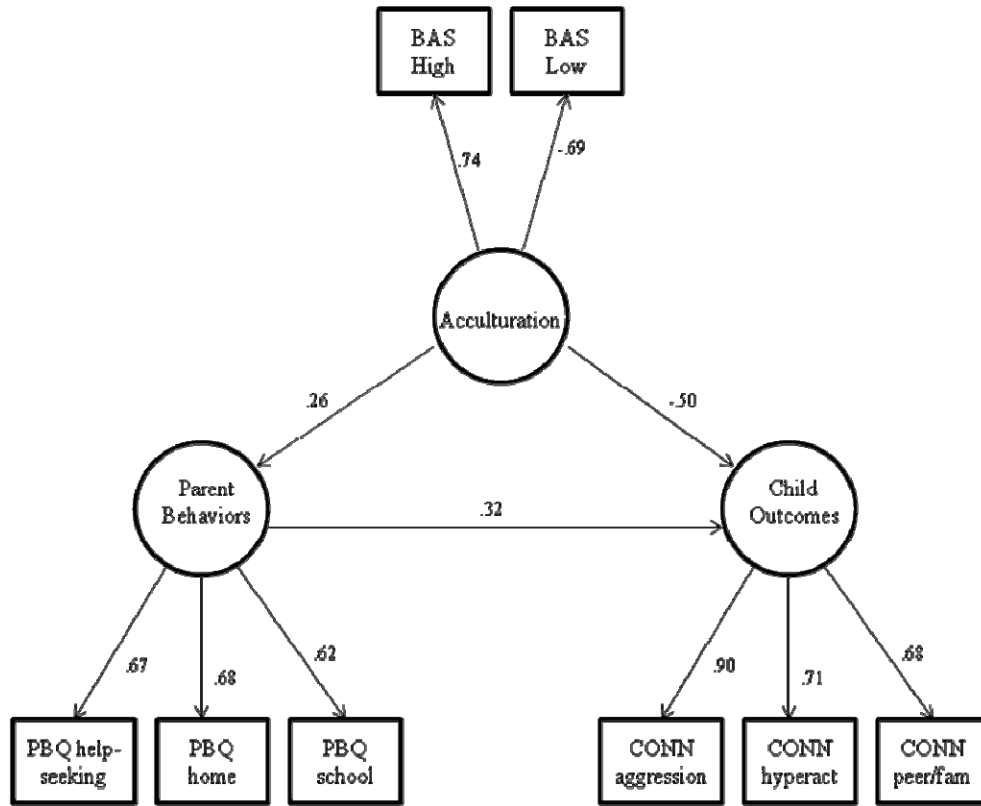


Figure 4. SEM of impacts of acculturation on parent behaviors and child outcomes.

The Acculturation model includes three latent factors. Latent constructs are represented by circles, and measured variables are represented by rectangular boxes. Arrows indicate the expectation of a hypothesized effect. Factors are described below:

Factor 1: Acculturation, a latent factor, was defined by two scales from the Bidimensional Acculturation Scale for Hispanics (BAS) (*BAS Hispanic (Low)*, *BAS non Hispanic (High)*).

Factor 2: Parent Behaviors, a latent factor, was defined by three FA-derived factors from the PBQ, and included *pro-learning behaviors at home*, *pro-learning behaviors at school*, *help-seeking behaviors* scales.

Factor 3: Child Outcomes, a latent factor, was defined by three items from the CRS scale; *problems with aggression*, *problems with hyperactivity*, *problems with peer/family relationships*.

As hypothesized, acculturation predicted both pro-learning parenting behaviors and child outcomes. The final model with standardized coefficients can be seen in Figure four.

Acculturation, a latent factor, was well defined by each of its measured variables: High acculturation (fixed = $-.742$, $t = 2.26$, $p < .05$); Low acculturation (standardized coefficient = $.689$, $t = 2.89$, $p < .05$).

Parent Behaviors, a latent factor, was well defined by each of its measured variables: Help-seeking behaviors (fixed = $.675$, $t = 3.63$, $p < .05$); Pro-learning behaviors at home (standardized coefficient = $.677$, $t = 3.60$, $p < .05$); Pro-learning behaviors at school (standardized coefficient = $.616$, $t = 4.25$, $p < .05$).

Child Outcomes, a latent factor, was also well defined by each of its measured variables: problems with aggression (fixed = $.900$, $t = 1.64$, $p < .05$), problems in hyperactivity (standardized coefficient = $.711$, $t = 4.45$, $p < .05$); problems with peers/family relationships (standardized coefficient = $.675$, $t = 4.77$, $p < .05$).

Further, an independent samples t test revealed that non-acculturated parents ($M = 2.65$, $SD = .89$) displayed significantly lower help-seeking behaviors compared to more highly acculturated parents ($M = 3.07$, $SD = .76$, $t(68) = 2.08$, $p = .04$). Acculturated parents (those who scored high on the non-Hispanic orientation scale) also had children with fewer problems with aggression ($M = 55.35$ vs. 63.4 , $t(67) = -2.04$, $p < .05$) and peers/family relationships ($M = 60.55$ vs. 71.22 , $t(67) = -2.60$, $p < .01$). Acculturated

parents also reported marginally more knowledge of school and academics ($M = 3.93$ vs. 3.60 , $t(65) = 1.78$, $p < .08$). None of the other parenting behavior or attitudes scales differed according to non-Hispanic orientation.

CHAPTER 5

DISCUSSION

Contrary to the hypothesis, the parenting factors of higher parental knowledge and self-efficacy did not directly predict higher neurobehavioral functioning; it was the child's quality of life that was most significantly related to these factors. Parent knowledge and self-efficacy, then, appears to most directly impact the child's health related quality of life and indirectly impact neurobehavioral late effects, at least from the parent perspective in this particular sample.

Across all of the parenting factors, parent self-efficacy appeared to be most strongly related to child neurocognitive functioning through health related quality of life (HRQOL). Overall, Latino parents with greater knowledge and self-efficacy reported they had children with better functioning on the PedsQL and therefore fewer problems on the Conners. Of course it may also be true that parents whose children were higher functioning felt more efficacious in their parenting efforts.

Parents of younger children (12 and younger) also reported more pro-learning behaviors at school, pro-learning behaviors at home, more knowledge of school and academics, and marginally more self-efficacy. Parent pro-learning behaviors in the form of help-seeking had the greatest impact on child executive function; none of the other pro-learning behaviors were significantly related to child neurocognitive outcomes as predicted.

Another important consideration in these results is the age of the sample; nearly half (48%) were over the age of 12 when diagnosed with cancer. Research shows that age at diagnosis is a major predictor of neurocognitive outcomes in children, with those who

are younger having worse outcomes (NCI, 2011). Additionally, children who receive cranial radiation also fare much worse than those who do not; in the current sample, 14% received cranial radiation, 21% received craniospinal radiation, and the remaining patients (65%) received no radiation (Moore, 2004; Mabbot et al., 2008).

Acculturation

Parents who were more highly acculturated had children with fewer behavioral adjustment problems, sought more help and information (scored higher on the help-seeking behaviors measure), and had more academic knowledge. However, acculturation was unrelated to child cognitive functioning. Acculturated parents (those who scored high on the non-Hispanic orientation scale) had children with fewer problems with aggression and peer/family relationships, but none of the other Conners or PedsQL scales differed according to non-Latino orientation.

Acculturated parents also reported more help-seeking/relationship building and marginally more knowledge of school and academics. Since the majority of this sample consisted of Spanish speaking immigrants, this is not a surprising finding. The language barrier alone would present a considerable obstacle when it comes to surmounting the academic challenges many of these families are facing. That, in addition to gaining access to the vitally needed resources for a child recovering from cancer, adds to the dilemma. How to help such families bridge the gap between cultural barriers and utilization of resources remains a major challenge. In this sample, for example, while 92% of parents ($n = 67$) reported their child experienced some type of learning difficulty in school, only 34% of the children had an individualized education program or were

utilizing special education services, yet these parents overwhelmingly reported they felt a strong sense of responsibility for their child's educational needs ($p < .01$).

It appears as though targeting parent self-efficacy may be the most important path to serving this population.

Concerns of Parents

It is also possible that higher acculturation contributes to higher SES and education, which in turn might allay some of the stressors that many of these parents face. While parental level of stress did not appear to directly impact child outcomes ($p > .05$), nearly every family in this sample (79.5%) reported some form of stress; for the majority (71%), financial stress was the main concern. Access to healthcare was another concern, with 21% reporting problems with health insurance as a source of stress, and 16.1% reporting transportation problems as a stressor.

In order to understand how Latino families respond to having a child with cancer, it is important to understand the cancer experience while taking into consideration language, culture, values, beliefs, and customs of the Latino family. In addition, SES and education level of parents facing the challenge and stress of caring for a child with cancer must also be taken into consideration. For example, Marshall et al. (2011) found that in Mexican American families, individuals looked to those that were known and comfortable to them (family, friends) when looking for resources about cancer before seeking information from those unfamiliar to them (professionals). This tendency, however, can have positive or negative effects, depending upon the resource the family turns to for help and counsel.

Other factors come into play as well, including the financial resources available to the family; medical insurance and access to quality medical care are certainly key contributors to the level of support and intervention a family receives. Further, factors such as education, degree of acculturation, and English proficiency will all have an enormous impact on an individual's beliefs and behaviors toward healthcare and healthcare providers.

Since we are looking at how to understand what is most important to these families, it might be important to gather more information in order to understand how best to serve this population.

Conclusion

The value that those from collectivistic cultures place on family and those most familiar to them is an important consideration in understanding the cancer experience from the perspective of the Latino. It is easy to misunderstand a lack of participation in groups or making use of other resources for these parents as having an attitude of indifference or capriciousness. These parents placed a high value on family interaction, and reported significant problems when their child suffered in that area. Further, knowledge of how to help their child with socialization was what most strongly correlated with parent self-efficacy for this sample. Treating the Latino pediatric cancer patient, then, must take such factors into consideration. While children can clearly be treated and often cured of cancer thanks to modern medicine, concerns for quality of life still remain; these very vital cultural issues are part of that equation.

Intervention programs to improve outcomes in Latino children, then, based on the results, would appear to indicate that increasing knowledge about specific study strategies will not be helpful for this group of parents with respect to improving cognitive and school success. Perhaps helping unacculturated parents improve their ability to access resources for their children (help-seeking) might be more beneficial. As we understand the concern of the parent and do so from a culturally sensitive perspective, helping parents feel empowered and equipped to improve their child's quality of life might be more important. It was interesting to note that parents of children with more psychosocial problems (problems with peer/family relationships, problems with aggression) appeared to be engaging in more pro-learning behaviors at school. Perhaps this was indicative of the value parents place on this aspect of their child's recovery process and their concern that positive interaction with others be treated as a priority. Future studies might focus more on this psychosocial aspect of the child recovering from cancer and cancer treatment, as the majority of studies to date appear to focus on cognitive outcomes relating to these factors.

Additionally, interventions targeting the entire family and not just the child are an important consideration. While therapeutic interventions can clearly be beneficial, research has shown that survivors of childhood cancer are at risk for depression and suicide in adulthood. According to the NCI (2010), several factors impact psychological adjustment in the survivor of childhood cancer. A study by (Recklitis et al. (2006) found that symptoms of suicidality were related to both cancer treatment type and post-treatment mental and physical health. Elevated risk for these patients was positively associated with younger age at diagnosis, cranial radiation treatment, leukemia diagnosis,

pain, hopelessness, and physical appearance concerns. Perhaps our efforts in this area should be more focused on the entire family.

Limitations

Although the current study provides supportive evidence for the tested models, several limitations should be considered. First, the results may not be generalizable to individuals of other cultures or nationalities. This sample consisted of Latino parents/caretakers who were predominantly Spanish speaking; 85% were born outside the United States. It is also possible that some of the very behavior-specific instruments used, such as the Conners Parent Report, may not have been appropriate for this particular sample.

These data come from parent self-reports and are therefore vulnerable to bias of individual perception and recall. Research shows that parent reports, especially when it comes to their child's HRQOL, often differ than child self-reports, particularly in adolescent children (Hinds, 2010). Further, not all of the instruments used in this study have been psychometrically validated in the literature, including the PBQ and PKEQ. Sample size was somewhat small for these purposes. These instruments were also translated into Spanish, which could have had some impact on how respondents understood the intended meaning of questions. Since some of the empirically derived factors appear to have items that tap into divergent constructs and do not have strong face-validity, future research might involve further refining of the PBQ and PKEQ for this specific population.

Finally, the results of the present study are based on cross-sectional data:
therefore, causality cannot be inferred.

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APPENDIX A

INFORMED CONSENT

Principal Investigator: Sunita Patel, Ph.D.

Telephone number: 626-301-8426 x60062

Co-Investigators: Smita Bhatia, M.D.; Jessica Dennis, Ph.D.; Elvia Barboa, M.A.

Department/Division: Behavioral Sciences Division, Departments of Population Sciences and Pediatrics

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

Parenting Behaviors in Latino Childhood Cancer Survivors

- I. **PURPOSE OF THIS RESEARCH STUDY:** You are being asked to participate in this research study because you are the parent or caregiver of a child who is a survivor of leukemia or brain tumor and who received chemotherapy or radiation as part of his/her treatment. The purpose of this study is to learn about how the quality of life of your child following cancer, particular with respect to his or her learning and thinking progress. We seek to understand how parents can benefit from educational programs designed to help parents help their child do well in school. We are particularly interested in understanding the needs for specific knowledge and skills training in Latino parents, including Spanish-speaking parents. Our long-term goal is to make improvements in existing programs to better fit the needs, knowledge, and preferences of the Latino community. Your participation in this study is expected to last 50 minutes
- II. **BACKGROUND:** Research has shown that children who have survived cancers involving the central nervous system (brain and spine) or who have had intensive treatment such as cranial radiation and/or intrathecal chemotherapy may experience difficulties in learning, academic achievement, and emotional well-being in the years following their treatment completion (i.e., neurobehavioral late effects). Research with children diagnosed with other chronic illnesses, as well as with cancer survivors, suggests that various educational programs can improve the child's academic achievement and well-being. Some of these programs have involved a family-oriented approach, where parents have been supported and trained to use a number of strategies within the home to teach their child skills, monitor their child's learning, and encourage their children to make improvements. Researchers are learning that there are many ways that parents can impact their

children's outcomes after serious illnesses such as cancer, especially when parents understand the increased educational needs of their child. Studies suggest that parents' helping or "pro-learning" behaviors at home sometimes make the difference between children who do poorly in school and those who do well. We have a study in progress that is examining family programs for childhood cancer survivors, but it is directed toward English speaking parents. This study is designed with the preferences and belief systems of individuals from the mainstream American culture. An important next step is to culturally adapt and tailor the intervention to meet the needs of those non-English speaking families.

- III. **WHAT WILL BE DONE:** Parents/caregivers of children aged 5 to 18 years will be asked to complete a set of questionnaires at the time of consent. We will either mail or give you the questionnaires to complete using a pencil, and return to our project in an envelope. If you prefer, a member of the research team can read the questionnaires to you and record your responses. This can be done over the phone or we can make an appointment for you to meet with someone from the research team. The questionnaires will ask you about your beliefs and behaviors regarding your child's academic and school issues, your knowledge of ways to help your child learn better, and how often you participate in school and learning-related activities. We will also ask you to rate your child's current quality of life and functioning, including indicating the presence of any problems with learning, inattention, and behavior. Finally, we will ask you about your child's motivation for school, information about your family, your cultural and language preferences, and your interest in learning about ways to promote your child's learning and school success. The set of questionnaires will take approximately 50 minutes to complete, but may take longer if the questionnaires are administered out loud.

HOW INFORMATION WILL BE PROTECTED: Information such as the questionnaires that you complete and your child's health information will be kept in a coded form and will not be attached to your/your child's name. The researchers will store the code in a secure area and allow only the study team (researchers) to have access to this code. This code will be kept in order to maintain a link between your/your child's name and the information created and collected about you/your child during this study in case there is a need to verify or clarify any of the information.

- IV. **POSSIBLE BENEFITS:** You may benefit from participation in this study if answering the questionnaires and reporting about your experiences and needs and those of your child helps you gain greater understanding about how you/your child can improve and manage the effects of cancer and its treatment on academic

performance and behavior. Other parents and their children in the future may also benefit from the information gained from your participation in this study.

- V. **POSSIBLE RISKS AND DISCOMFORTS:** While participating in the study, you may become tired from the amount of time needed to fill out the questionnaire. The questionnaire will focus on life issues that could cause you to become emotionally upset. Sometimes being asked to report about personal experiences and activities makes a person more aware of things going well or not so well for them. If you should become upset, a member of the research team will discuss these feelings with you and will contact Dr. Patel, or a designated member of the pediatric psychosocial unit. He or she will notify other members of the care team who will be able to suggest sources who can help you with the difficulty you are experiencing. Support and counseling will be available from social workers and psychologists as needed.
- VI. **ALTERNATIVES TO PARTICIPATION:** Your alternative is to not participate in this study. If you choose not to participate in this study, your decision will not affect your ability to participate in future research or receive treatment at City of Hope.
- VII. **CONFIDENTIALITY OF INFORMATION AND AUTHORIZATION TO USE AND DISCLOSE YOUR PROTECTED HEALTH INFORMATION FOR PURPOSES OF THIS STUDY:** As part of this research, you are/your child is agreeing to allow City of Hope National Medical Center (City of Hope) to use and disclose (share with others) your/your child's protected health information (PHI) in connection with this study. PHI refers to your/your child's demographic information (your/your child's name, where you/your child live(s), your/your child's telephone number, your/your child's age, etc.), and your child's medical record. This includes, for example, your child's medical history, including his/her cancer diagnosis and type of treatment received for cancer.

Your/your child's PHI will be shared, used and disclosed for the purpose of conducting this study as indicated on the first page of this consent. Your/your child's PHI will also be used to keep the research sponsor informed about this research and reporting to oversight/regulatory agencies.

The people authorized to use and share your/your child's PHI for purposes of this study include the principal investigator and the research team (the investigators listed on this consent form); the staff supporting the research team; your/your

child's City of Hope physicians and treatment team; and the Health Information Management Services Department (Medical Records).

Your/your child's PHI will be shared, as necessary with the City of Hope Institutional Review Board (IRB), other City of Hope research regulatory committees and the City of Hope Cancer Protocol Review and Monitoring Committee (CRSMC). Your/your child's information will also be shared, as necessary/appropriate with employees of the research sponsor who are involved in the administration of this study. You/your child are also allowing the research team to share your/your child's PHI with the Office for Human Research Protections (OHRP), and with any person or agency as required by law.

All uses and disclosures of your/your child's PHI for this study will be made as a result of this authorization. Any additional uses and disclosures will be in accordance with City of Hope's Notice of Privacy Practices or will occur only after separate permission is obtained from you/your child. Use and disclosure of your/your child's PHI will continue until the research study has been completed and the study file closed.

Once your/your child's PHI has been given to a third party (for example, an individual or agency outside of the City of Hope), it may be subject to further disclosure and is not protected by City of Hope from further use or disclosure.

The information from this study may be published in scientific journals or presented at scientific meetings; however, your/your child's identity will be kept confidential.

You may revoke this authorization to use and disclose your/your child's PHI at any time by contacting City of Hope's Privacy Officer at (626) 359-8111 ext. 64025 and asking for the ***Revocation of Authorization for Use of Protected Health Information for Research***. Fill this form out and return it as the form instructs. If you revoke this authorization to use and disclose your/your child's PHI, you/your child will no longer be able to participate in this study. The researchers and others involved in conducting this study will no longer be able to use or disclose your/your child's PHI for this research, except to the extent they have already relied on this authorization such as for purposes of maintaining the integrity of this study and for regulatory purposes. This means that any uses and disclosures made by City of Hope prior to receiving your Revocation form cannot be taken back. While no further PHI will be shared for this study, your/your child's PHI already shared and used will continue to be used in the overall study.

Your decision to revoke this authorization to use and disclose your/your child's PHI as part of this study will not affect your/your child's ability to obtain routine care at City of Hope.

- VIII. **OFFER TO ANSWER QUESTIONS**: The principal investigator, Dr. Sunita K. Patel, responsible for your care or treatment, has offered to and has answered any and all questions regarding your participation in this research study. If you have any further questions, you can contact Dr. Sunita K. Patel at (626) 256-HOPE (4673) ext. 60062.
- IX. **SPONSOR OF THIS RESEARCH**: City of Hope is the sponsor of this study. The study will be funded as a series of small projects funded by a NCI P20 COH-CSULA collaborative research grant.
- X. **COST TO THE SUBJECT FOR PARTICIPATION**: Your insurance carrier will not be charged for participation in this study.
- XI. **PAYMENT TO THE SUBJECT FOR PARTICIPATION**: As a gesture of appreciation for your time and contribution to this research, we will provide a \$15.00 gift card to the participating parent/caregiver.
- XII. **VOLUNTARY PARTICIPATION WITH RIGHT OF REFUSAL**: Your participation in this research study is voluntary. You are free to withdraw your consent for participation in this study without any loss of benefits, penalty, or interference with any future treatment at City of Hope.
- XIII. **IRB REVIEW AND IMPARTIAL THIRD PARTY**: This study has been reviewed and approved by the Institutional Review Board (IRB). A representative of that Board, from the Research Subjects Protection Office, is available to discuss the review process or your rights as a research subject. The telephone number of the Research Subjects Protection Department is (626) 256-HOPE (4673) ext. 62700.
- XIV. **FINDINGS RELATING TO WILLINGNESS TO CONTINUE PARTICIPATION**: You will be informed of any significant new findings related to this study which might affect your willingness to continue to participate.

XV. **EXPERIMENTAL SUBJECT'S BILL OF RIGHTS AND CONSENT FORM:**

You have been given a signed copy of this consent form and the "Experimental Subject's Bill of Rights" and have read them.

Signature for consent: By signing this consent form, you are making a decision to participate in this research study. Your signature on this informed consent form indicates that you have read and understood the information in this form. You have also had the information in this form explained to you. You have had a chance to ask questions and had these questions answered to your satisfaction. You have been informed that you will receive a copy of this signed consent form.

I hereby agree to be a research subject in this research study:

Print Father's Name: _____

Father's Signature: _____

_____ Date: _____

(date must be in father's handwriting)

Print Mother's Name: _____

Mother's Signature: _____

_____ Date: _____

(date must be in mother's handwriting)

Print Caregiver's Name: _____

Caregiver's Signature: _____

_____ Date: _____

(date must be in caregiver's handwriting)

* Subject's Legally

Authorized Representative

_____ Date: _____

(if subject unable to sign) (date must be in representative's handwriting)

Witness's Signature: _____

_____ Date: _____

Investigator's Signature: _____

_____ Date: _____

(If applicable) I have translated this form into the _____
language.

Translator's Signature:

_____ Date: _____

* If signed by other than subject, indicate relationship (e.g., mother, father, husband,
wife, daughter, son, etc.): _____

**Phase I Trial of Intraperitoneal nab-Paclitaxel (Abraxane®) in the Treatment
of Advanced Malignancies Primarily Confined to The Peritoneal Cavity**

**AUTHORIZATION TO USE AND DISCLOSE YOUR PROTECTED HEALTH
INFORMATION (PHI) FOR PURPOSES OF THIS STUDY**

- I. **Purpose of this Authorization:** The information about your health is something that is protected by law and cannot, except for certain purposes, be disclosed (shared) without your permission. As part of this research, you are agreeing to allow City of Hope National Medical Center (City of Hope) to use and share with others your personal health information (PHI), as needed for the research. If you agree to participate in the study named above (called the “Study”), you must sign this consent form in addition to the Study Consent Form.
- II. **The Information About You that is Covered By this Authorization:** PHI refers to information that we maintain about you that identifies you and includes the information contained in your medical record. Your medical record consists of information related to your health and the treatment we provide to you, such as your medical history, the results of physical exams, blood tests, x-rays and other diagnostic and medical procedures. If you sign this form, you are allowing City of Hope and the individuals indicated below to use and share any PHI we maintain about you that is required for your participation in the Study.
- III. **Purposes for Uses and Sharing of your PHI; Who Will Use, Share and Receive your PHI:** Your PHI will be used and shared with others for the purpose of doing this research as described in the Study Consent Form. Your PHI will also be used to keep the research sponsor informed about this Study, for reporting to those individuals and authorities responsible for overseeing our research activities to make sure that the activities are properly conducted, and to report to regulatory agencies as required by the Study.

The people authorized to use and share your PHI for purposes of the Study include the Principal Investigator and the research staff supporting the Study; your City of Hope physicians and the health care team; and the Health Information Management Services Department (Medical Records Department). This also includes any agents or contractors used by these individuals or groups for purposes of conducting or managing this Study. At the City of Hope, the Institutional Review Board (IRB) and other City of Hope research regulatory committees will have access to your PHI as necessary to monitor research. In addition, at the City of Hope, the Cancer Protocol Review and Monitoring Committee (CRSMC) will have access to your PHI as necessary to monitor research.

You are also allowing your PHI to be shared with the Office for Human Research Protections (OHRP) and with any person or agency as required by law. In

addition, certain other regulatory agencies, including, the Food and Drug Administration (FDA) will have access to your PHI.

Your information will also be shared, with The National Cancer Institute (NCI), PADRES Contra El Cancer (PADRES) and its employees, agents or contractors who are involved in the administration of the Study and with California State University Los Angeles.

By signing this consent form, you also authorize disclosure of your PHI by other health care providers outside the City of Hope to be given to the City of Hope investigator and/or the City of Hope research team for follow-up purposes. This follow-up information may include results of laboratory tests, physical examination, radiological tests, and other information about you.

This authorization will allow us to use and share your PHI for the Study. No other additional uses and disclosures other than for the purposes of the Study are included in this authorization. City of Hope's Notice of Privacy Practices will continue to protect your non-Study information. If necessary, another separate permission will be obtained from you for any non-Study uses or sharing of your PHI.

- IV. **Expiration of this Authorization:** This authorization to use and share your PHI will expire twenty-five (25) years from the date that you sign this authorization.
- V. **Further Sharing of Your PHI:** Your privacy is important, and this is the reason for having rules which control who can use or see your PHI. City of Hope maintains control over your PHI at present, but once we share this information with a third party (for example, an individual or agency outside of the City of Hope), then it is no longer possible to maintain the same level of protection. The persons outside our control may not be governed by federal or state privacy laws, and it is possible that they could share your PHI with others for whom you have not given permission.

The information from this Study may be published in scientific journals or presented at scientific meetings, but your identity will be kept confidential.

- VI. **Your Rights Under this Authorization:** You may cancel this permission to use and share your PHI at any time by contacting City of Hope's Privacy Officer at (626) 256-HOPE (4673) ext. 64025. You should ask for the **Revocation (Cancellation) of Authorization for Use of Protected Health Information for Research**. Fill this form out and return it as the form instructs. Your cancellation begins when the Health Information Management Department of City of Hope

receives this form. If you cancel this authorization to use and share your PHI, you will no longer be able to participate in the Study. This is because the research under this Study cannot be conducted without your PHI.

Once you cancel your permission to use and share your PHI, the researchers and others involved in conducting the Study will no longer be able to use or share your PHI for this research. PHI already used and shared up to this point as part of this Study will continue to be used for purposes of this research. This means that any uses of your PHI and any PHI shared about you by City of Hope prior to receiving your cancellation (revocation) form cannot be taken back. While no further PHI about you will be shared for the Study, your PHI already shared will continue to be used in the overall Study.

VII. Signing this Authorization is Your Choice: Your ability to obtain care at the City of Hope will not be affected by your decision to sign this authorization form. You will be able to continue to receive health care at City of Hope if you choose not to sign this authorization form or if you sign this form and later cancel your permission to use and share your PHI.

If you agree to the use and sharing of your PHI, please sign below. You will be given a copy of this authorization form.

Print Father's Name: _____

Father's Signature: _____

Date: _____ (date must be in Father's handwriting)

Print Mother's Name: _____

Mother's Signature: _____

Date: _____ (date must be in Mother's handwriting)

Print Caregiver's Name: _____

Caregiver's Signature: _____

Date: _____ (date must be in Caregiver's handwriting)

* Subject's Legally

Authorized Representative _____ Date: _____
(if subject unable to sign) (date must be in representative's handwriting)

Witness's Signature: _____ Date: _____

Investigator's Signature: _____ Date: _____

(If applicable) I have translated this form into the _____
language.

Translator's Signature: _____

Date: _____

* If signed by other than subject, indicate relationship (e.g., mother, father, husband,
wife, daughter, son, etc.):

EXPERIMENTAL SUBJECT'S BILL OF RIGHTS FOR PSYCHOSOCIAL STUDIES

You have been asked to participate as a subject in an experimental clinical procedure. Before you decide whether you want to participate in the experimental procedure, you have a right to:

1. Be informed of the nature and purpose of the experiment;
2. Be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized;
3. Be given a description of any attendant discomforts and risks reasonably to be expected from your participation in the experiment;
4. Be given an explanation of any benefits reasonably to be expected from your participation in the experiment;
5. Be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous to you, and their relative risks and benefits;
6. Be informed of the avenues of medical treatment, if any, available to you after the experimental procedure if complications should arise;
7. Be given an opportunity to ask any questions concerning the medical experiment or the procedures involved;
8. Be instructed that consent to participate in the experimental procedure may be withdrawn at any time and that you may discontinue participation in the medical experiment without prejudice;
9. Be given a copy of this form and the signed and dated consent form; and
10. Be given the opportunity to decide to consent or not to consent to the medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on your decision.

APPENDIX B

APPROVAL LETTER

October 14, 2008

Sunita Patel, PhD.
Clinical Neuropsychologist
Director, Behavioral Research in Pediatrics
Division of Population Sciences
Division of Pediatrics, City of Hope
National Medical Center
Building #173, 1500 E. Duarte Road
Duarte, CA. 91010-3000



Dear Dr. Patel,

I am writing to express my commitment to, and support for, your research proposal titled **"Parenting behaviors in Latino childhood cancer survivors at risk for neurobehavioral late effects."** As Chief Executive Officer for PADRES Contra El Cáncer (parents against cancer) I can't tell you how valuable your work is to our community.

Founded in 1985, Padres Contra El Cáncer (PADRES) was created after two research studies funded by the American Cancer Society indicated that culturally-relevant educational and emotional support services for the Latino patient were lacking in the medical setting. The outcome of the study influenced the medical community to recognize education and emotional support as vital health-related services in ensuring success of the treatment plan and the survival of the child.

PADRES Contra El Cáncer's mission is to improve the quality of life for Latino children with cancer and their families. We strive to alleviate the challenges caused by cancer through the development and implementation of educational, emotional, social and financial programs. While pediatric cancer centers provide optimal medical attention for these children, PADRES works towards providing educational guidance, crisis intervention counseling, financial assistance and referrals to social resources.

PADRES represent a large Hispanic, Spanish speaking population. Through our programs we have learned that SES and cultural factors often influence and can undermine new cancer treatment and survivorship care. The need for support becomes more challenging for those children with CNS disorders or those children at risk for cognitive deficits due to their cancer treatment regimen. Your proposed research has the potential to greatly enhance a family's abilities to respond to the

child's cognitive and learning needs. We are excited that your study will learn how to help our parents support their child's academic and learning needs at home.

The PADRES Board of Directors met last month and reviewed and approved your current proposal to work with the PADRES population on the current study. Once passed through your final IRB review, I will assign to PADRES representatives to work with you in family recruitment in the study. Please feel free to contact me with any additional questions on the current study at 323.850.7901 x222.

Warm Regards,

A handwritten signature in black ink, appearing to read 'E. Barboa', with a stylized flourish at the end.

Elvia Barboa, M.A

CEO